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Envisioning Shared Decision Making: A Reflection for the Next Decade

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Abstract

Despite the evolving evidence in favor of shared decision making (SDM) and of decades-long calls for its adoption, SDM remains uncommon in routine care. Reflecting on this lack of progress, we sought to reimagine the future of SDM and the path to take us there. In late 2017, a multidisciplinary and international group of six researchers were challenged by a senior SDM scholar to envision the future and, based on a provocatively critical view of the present, to write letters to themselves from the year 2028. Letters were exchanged and discussed electronically. The group then met in person to discuss the letters. Since the letters painted a dystopian picture, they triggered questions about the nature of SDM, who should benefit from SDM, how to measure its contribution to care, and what new ways can be invented to design and test interventions to implement SDM in routine care. Through contrasting the purposefully generated dystopias with an ideal future for SDM, we generated reflections on a research agenda for SDM. These reflections hinged on recognizing SDM's contributing to care, that is, as a way to advance the problematic human situation of patients. These focused on three distinct yet complimentary contributors to SDM: 1) the process of making decisions, 2) humanistic communication, and 3) fit-to-care of the resulting decision. The group then concluded that to move SDM from envisioned to routine practice, and to ensure it reaches all, particularly persons rendered vulnerable by current forms of health care, a substantial investment in implementation research is necessary. Perhaps the discussion of these reflections can contribute to a path forward that will improve the likelihood of the future we dream for SDM.

Keywords

decision aids, implementation, patient-centered care, shared decision making

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Today, shared decision making (SDM) is increasingly recommended as a valuable approach in shaping care.^{1,2} The scientific community has responded by conducting work on SDM models and techniques,^{3,4} developing and evaluating training and tools to foster SDM,^{5,6} implementing SDM in routine care,^{7–10} and assessing its occurrence, quality, and consequences.^{3,11–14}

In 2007, O'Connor and colleagues reviewed the progress and needed policy changes to achieve the “tipping point” for the adoption of SDM in practice.¹⁵ Yet, more than a decade later, SDM remains uncommon in routine care everywhere.^{1,7,11,16}

Reflecting on this lack of progress, a group of early to mid-career researchers—colleagues and collaborators from

diverse backgrounds (some clinicians, others with expertise in design, implementation science, measurement), active in the field of SDM research, and working in North America, South America, and Europe were challenged by a senior SDM scholar (VMM) to envision a path for SDM. To do this they wrote letters in which they each created a provocative, often dystopian, account of SDM in the future (2028) or as it is understood and practiced in 2017. These provocations served to highlight issues for further reflection. In late 2017,

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these letters were exchanged and discussed electronically (see the online appendix).

The letters triggered questions about the nature of SDM, who should benefit from SDM, how to measure its contribution to care, and what new ways can be invented to design and test interventions to implement SDM in routine care. The group then met in person to discuss the ideas generated from those letters. Unsettled, uncomfortable, and concerned from that vista, the group gathered their reflections and resolved to formulate a path forward for SDM, one that may prevent the troubling vision we imagined and make more likely the future we dream for SDM. What follows is a description of our reflections on four aspects of SDM and our vision for the future: 1) What is the purpose of SDM, 2) equity and SDM, 3) measurement, and 4) implementation.

A Future SDM: Reflections

From the discussion of the stories of the future, the group identified and discussed four broad questions: what is SDM, who should benefit from SDM, how to measure its contribution to care, and what new ways can be invented to design and test interventions to implement SDM in routine care. These led to the formulation of a path forward for SDM. These reflections did not result from a methodologically rigorous process but from a discussion among colleagues of the results of the provocations and the issues that they raised. These impressions are not proposed from a position of authority, which this group lacks, but are offered up for consideration and discussion by the larger SDM community.

The Purpose of SDM

SDM has been invoked as a solution to faulty decision making, insufficient patient involvement, or evidence

uncertainty.^{17–19} Yet, these are not problems of care. Let us take the example of Mr. Jones, a 70-year-old man with new-onset atrial fibrillation who presents to the emergency department. He has a history of frequent falls and is concerned about his ability to care for his disabled mother. Mr. Jones must face a new diagnosis in the context of his life and of his responsibility for the care of his aging mother. In short, Mr. Jones finds himself caught in a situation that is troubling, confused, disorienting, and disabling. It is a result of this situation that he seeks help from health care, and it is as a result of this situation that Mr. Jones and his clinicians make decisions together. Notably, his situation does not arise from issues of evidence or lack of information (i.e., it will not be solved by finding and reviewing pertinent research summaries) or lack of engagement (since Mr. Jones is quite engaged in living and working through his situation). Rather, his situation is a human problem that requires action, and SDM helps identify, shape, and initiate the action that the situation demands.

We recognize that SDM refers, albeit more broadly than usually described,^{3,20–22} to the various approaches to care in which patients and clinicians work together to advance the problematic human situation of a patient. This account of SDM extends SDM's historical concern for patient and clinician roles, involvement in decisional processes, rights and responsibilities, and general determinants of decisions.²³ It grounds the purpose and future development of SDM in the need to work through how to act and care for each patient's suffering. The different kinds of situations in which patients and clinicians find themselves calls for different ways of addressing these problems together. Therefore, there should not be a single form (or definition) of SDM but several modes of SDM each with its own methods that are determined by and developed to attend to a particular individual or family's suffering.^{24,25} The kind of research that follows from clarifying the purpose of SDM methods must investigate how and to what extent SDM contributes to the resolution of troubling human situations across these modes.

As a method of care, SDM must adapt to respond to different problems. For instance, the purpose of SDM in the care of a patient with uncontrolled diabetes may call for the discussion of the comparative advantages and disadvantages of available diabetes medications to achieve concordance between the attributes of these medicines (e.g., weight loss, ability to lower A1c levels, risk of hypoglycemia) and the preferences of the patient. Meanwhile, the purpose of SDM in the care of a dying patient in the intensive care unit may require empathy, solidarity, and

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dialogue to reflect on existential issues and discover what humanly matters, with less emphasis on the discussion of alternative options and their attributes. Confusion of purposes may lead to the perfect implementation of the wrong SDM approach, an approach that comes across as uncaring. An example of this confusion takes place at the bedside of critically ill patients who are offered a menu of life support options alongside their pros and cons, and are asked to select the ones that they would want.

What Is the Relationship of SDM to Patient-Centered Care? We see SDM as one way of caring for patients and their problems. We suggest that the point is not to use SDM to make care nominally more patient-centered. Rather, what makes SDM patient-centered (or not) is how it is used, *in each case*, to address the problems and experience of patients. These problems are the reason why patients and clinicians need to work together. Patient-centered communication, patient involvement, relationship building, and a holistic outlook are helpful in working with patients to address and honor problems; however, they do not by themselves make SDM patient-centered. They become patient-centered when they are used to help patients. Without connection to caring for the troubled experience of patients, these elements risk becoming token behaviors taken as a proxy for SDM.

SDM for All

How can we ensure that SDM practices will reach not only the privileged few who approach the clinic without barriers to participate as much as they need and want in crafting their own care but also to those for whom the system was not built? We must consider SDM's reach, which must encompass the care of those made vulnerable by barriers to communication or unjust policies—for example, those with limited health literacy, cognitive or sensorial constraints, speaking nonnative languages, and experiencing consequences of complicated legal and migratory status. Despite documentation of disparities in the quality of SDM,²⁶ the call to involve vulnerable populations in the design of SDM tools,^{27,28} and proposed frameworks and interventions to overcome patient-level barriers to involvement in care,^{29–31} implementation remains slow and requires awareness and persistence.³² Tudor Hart's inverse care law, where “good medical care tends to vary inversely with the need for it in the population served,” also seems to apply to SDM.³³

Although some early work suggests that SDM and SDM research are possible in vulnerable populations,^{34,35} a recurrent argument is that certain vulnerable patients

could not participate equally in SDM.³⁶ Most patients, however, can take part and want to be involved in crafting their own care.³⁷ This becomes even more evident when patients are not asked for their preferences for involvement in making the final decision, as is usually done using the Control Preferences Scale,³⁸ for example, but rather for their preferences in involvement in a process of SDM in which they work with their clinician *before* making that final decision.^{39,40} Moving forward we must ensure that SDM research and implementation focuses deliberately on those living and seeking care where care is more difficult and where more resources are needed to achieve the same goals. We must see each person in front of us as who they are and the human problem that they are experiencing. We must engage them in a conversation they are able to participate in, listen, and acknowledge and seek to overcome any barriers to their collaboration by any available means. The means to achieve equity in SDM may include the use of interpreters, plain language, clear communication,⁴¹ and technologies that ameliorate language and sensorial challenges. In all cases, high-quality SDM is determined by how well the resulting care fits as a sensible response to the patient's situation and this achievement should be pursued in all patients—not just the assertive and empowered ones.

Assessing SDM

As we orient toward the different purposes of SDM, it becomes important both in research and practice to relate how we assess its effects according to the fulfillment of these purposes. A systematic review of the quality of SDM instruments identified 40 different measures, focused on the process of SDM (*what* to do). It also found that the methods used in developing these instruments were not well reported and that there is a lack of evidence regarding measurement quality of many measures.¹³ Interestingly, most trials assessing the effects of SDM interventions do not use one of these SDM-specific measures but proxy measures for a successful SDM process, such as patient knowledge or decisional conflict.^{6,11,42}

To truly capture the occurrence of SDM, we need to shift our focus to assess how SDM contributes to care. This contribution could have three different but complementary components: 1) The process (“*what* to do”), to assess the technical steps of SDM depending on its purpose: for example, fostering of choice awareness, providing information, discussing values and preferences are all steps taken when the purpose of using SDM is to determine the evidence-based option that best matches patient preferences; 2) Humanistic communication (“*how* to do

Box 1. Our Approach

In 2017, a multidisciplinary and international group composed of six researchers met in the offices of the US Agency for Healthcare Research and Quality (AHRQ) to develop reflections on the future of SDM. The group comprised clinicians, a designer, and experts in communication and SDM assessment and implementation. Three worked in the United States, and one each in Canada, the Netherlands, and Germany. In preparation for the in-person meeting, each participant was asked to imagine the field of SDM in 2028, in 10 years, and to write, as a provocation, a letter from their future selves to their present selves. In writing these letters, two participants focused specifically on clinical care, two on assessment, and two on implementation and dissemination. In an electronic forum, participants shared their letters and appended comments and reflections to each one. Appendix offers key excerpts.

The group met in person (on December 13 and 14, 2017) to discuss their letters. During this process, a participant took notes in writing and on a board of the different topics emerging from the content of the letters and subsequent conversation. These initial topics were iteratively organized into themes. The group reviewed and refined the themes to make them coherent, distinct from each other, and conducive to the development of research recommendations. They focused on formulating recommendations to promote the full realization of SDM in the care of all patients and directed them to policymakers, research funders, researchers, implementers, and clinical decision makers (i.e., patients and clinicians).

it”), to ensure that, while taking the technical steps of SDM, practitioners demonstrate a commitment to the dignity and worth of each person, respecting the patient’s humanity and acting with compassion, integrity, and empathy in both the manner and the content of the interaction⁴³; and 3) Sense of the decision (“why do it”), to assess the extent to which the care formulated makes sense in the patient’s life intellectually (coherent, logical, and scientific), emotionally (honors and responds to the emotions of the situation), and practically (can be implemented).^{44,45}

We recently showed that patient evaluations of the process of SDM and of the quality or sense of the final decision, that is, the outcome of SDM, are only weakly correlated.⁴⁶ This would suggest a gap in the validity of SDM process measures to the extent that they fail to award the best score to the best care.⁴⁷ Recognizing that the purpose of SDM is to contribute to care by working through how best to respond the patient’s human problem, and that different modes of SDM are needed to respond to different kinds of problems, then the way to measure SDM should reflect which purpose SDM pursues in the situation under evaluation. If we misalign the purpose of SDM and measurement, or if we focus only on the SDM process (i.e., the technical steps) while neglecting the other elements, the assessment may “provide the illusion of good, better, or improved SDM, while favoring measurable SDM that is predominantly standard, technical, mechanical, and context-blind.”⁴⁷ Further research should focus on identifying and, if unavailable, developing, refining, and evaluating measures capable of capturing the extent to which SDM took place, how it took place, and how well the SDM approach contributed to resolving the problematic situation of the

patient. This work needs to take place for each of the different purposes of SDM.

Embedding of SDM

Contemporary medicine offers peculiar challenges to using SDM to care for each patient. For example, efforts to improve the value of health care may involve deploying financial incentives to promote SDM. Institutions may respond to these incentives, for example, by mailing a decision aid to a patient. This mail-out may seem to fulfill a requirement of high-value health care but paradoxically results in waste. Mailing of a decision aid or documentation of its use may not mean that SDM occurred but is often sufficient to meet requirements for payers to reimburse for services such as low-dose computed tomography screening for lung cancer.⁴⁸ Such policies devalue SDM, reducing it from a form of care to a tactic to reduce liability, to correct the over- or underuse of tests and treatments, and to reduce costs.⁴⁹

When SDM is considered as a procedure, separate from care, it is possible for a health care organization to deploy this procedure in a standardized way (e.g., embedding SDM tools in the electronic record for patients to review in preparation for key appointments). These efficiencies often require seeing what is common about patients and their situations rather than what is particular. To helpfully contribute to the care of each person, however, we echo our call of Hargraves and colleagues in that SDM needs to be carefully tailored to attend to what is particular about the problematic situation of each person.²⁵ This goes beyond making allowances for variation in settings, literacy, language, culture, and other traits of the patient. It requires asking the question, “What does

Table. Research gaps for consideration in the future of shared decision making		
Problem domains	Examples of specific gaps	Examples of Practical Responses
Clarify the purposes of SDM	<ul style="list-style-type: none"> • There may be several purposes and kinds of SDM when designing trials • Lack of utilization of a mixed methods approach to further define the purpose of SDM and compare/contrast different clinical settings 	<ul style="list-style-type: none"> • Pre-specify the mode and purpose of SDM when designing a study (Hargraves et al, PEC 2019)
SDM for all: Equity in SDM research	<ul style="list-style-type: none"> • Studies do not incorporate a “universal precautions” approach to health literacy (e.g., incorporate plain language and use of low literacy principles in development of tools, survey instruments) • Failure to include populations from safety-net settings in implementation studies of SDM 	<ul style="list-style-type: none"> • Involve multiple stakeholders, including patients with limited health literacy, in the development of interventions to promote SDM • Promote diversity in research staff • Oversample diverse populations in intervention studies
Assessing SDM (measurement)	<ul style="list-style-type: none"> • Scales do not currently <u>measure the contribution</u> of SDM to problems of care • Need to measure the process of SDM (“what to do”) depending on its purpose • Examine the extent to which SDM respect’s a patient’s humanity • Study the quality of the decision – need to measure the extent to which care makes sense in the patient’s life intellectually, emotionally and practically 	<ul style="list-style-type: none"> • In studies of SDM interventions, present scores on individual items or SDM elements when reporting (Kunneman et al MDM 2019)
Embedding of SDM: implementation and dissemination	<ul style="list-style-type: none"> • Examination of synchronous forms of communication in person v. telecommunication technologies and their impact on SDM is needed • Intended and unintended consequences of the impact of SDM interventions on policy and practice is unknown 	<ul style="list-style-type: none"> • Comparative effectiveness studies of tools vs. system change (e.g., test a point of care decision aid for depression treatments compared with patient-clinician directed flexible appointment times/spaces/frequency)

Figure 1 Research gaps for consideration in the future of shared decision making.

SDM need to be in order to help this particular patient and their problems?” and reinventing SDM in response.

We must embrace the notion that a decision does not occur at the point of selecting, agreeing on, or ordering a treatment but originates in the experience of the patient, develops over time through interaction with clinicians and friends and family members, and culminates in caring action.^{50–52} As seen most clearly in the care of patients with chronic conditions, care is formed over time and iteratively within the relationship of patient and clinician.⁵³ Implementation research must uncover, design, and evaluate ways by which health care systems can efficiently support the practice of SDM wherever care is formed. This may be in the context of high-stakes situations or in the routine care of patients with ongoing conditions. It may occur at places and times removed from the consultation and involve parties other than the clinician. Decision making may require more or less time

during a consultation, or take place within the continuity of a primary care relationship and taking one or more conversations.⁵⁴ This may call for innovations that bring SDM to both the point of care and to the point of life, and for interventions that support the emergence of SDM in the context of conversations taking place, either in person or virtually. Technologies that can support this expanded vision of SDM must be invented and tested for their ability to foster care.

SDM tools, such as decision aids, have been the primary technology developed and tested to implement SDM. Yet, this poses many challenges. Research studies that employed different approaches to disseminate point-of-care decision aids in varied clinical settings have yielded suboptimal results.^{55–57} Could future implementation studies of SDM move beyond the implementation of SDM tools and, as in prior studies, integrate professional training and cultural interventions,^{8,12,58,59} and,

for example, promote choice awareness in the consultation,⁵⁷ or pursue multicomponent SDM interventions which combine tools, training, and patient engagement?¹² Shifts in mindset, system, and culture changes⁶⁰ to promote the space and time (mental, physical, emotional, and even spiritual) for important conversations could be compared to the sole incorporation of tools alone or with coaching.

The successful normalization of a new complex intervention into established routines is eventually the achievement of people doing work.⁶¹ The work of implementation includes what patients and clinicians do, but also the activities of those responsible for determining the duration and interval of outpatient visits, or of the programmers of electronic workflows supporting clinical encounters. The exploration of how to conduct aspects of SDM with groups of patients may offer the opportunity to extend this form of care to more patients in low-resource settings. SDM teams may expand from the clinician-patient dyad to include the family and other informal caregivers⁵⁰ and diverse members of the health care and social support teams, especially in situations of medical and social complexity and multimorbidity. Group SDM represents an area in need of further research exploration.

The broad, international interest in SDM has also led to diverse policies designed to promote and enable SDM in practice.^{1,2} These policies, like any other complex intervention, deserve pragmatic and rigorous evaluation, ideally before widespread implementation.⁴⁹ These evaluations should ascertain the extent to which the body of acting policies (including the one under study) fosters the work people do to implement forms of SDM that are fit for purpose, to reach people often left out, and to achieve better care as assessed using meaningful and appropriate measures.

Discussion

The disquieting future we imagined led us to reflect on next steps that we think improve the odds of a better future for SDM. Given what we “saw” in the future, our exploration could not conform itself with merely tinkering with SDM “as is,” but required formulating new priorities that could inform the work of funding agencies, technology companies, and policy makers.

Our approach is, however, quite limited. Our reflections were generated through a creative process of writing letters from the future, an in-person 2-day long conversation and an exchange of ideas between a few colleagues. This viewpoint is limited in that it does not reflect a comprehensive systematic review of all SDM

literature or a comprehensive polling of all experts and stakeholders in the field. Its strength, however, lies in the collection of diverse perspectives from SDM researchers with different backgrounds and working in different settings, emboldened by their joint efforts, and unweighted by the chains of the practical present to envision a better future.

Conclusion

As we gaze back from an imagined unsettling future, we propose to recognize SDM as a method of care, one that flexibly adapts to the problems it seeks to resolve.²⁵ We propose that the overarching purpose of SDM is to find care that makes sense, fits the situation, helps resolve it, and honors the humanity of all involved in doing so.²⁴ Once we better appreciate the diversity of SDM and the purposes to which it contributes, we can then measure, implement, and disseminate more dignified and responsive ways for patients and clinicians to work together when caught in situations of suffering. Like life (and love), SDM as a form of care is complex and inherently messy. And yet, when driven by the need to care for individual persons and infused with love, SDM can be an effective form of medical care.

Birri, the Argentinean filmmaker, explained that utopias are like the horizon in that the horizon retreats as one walks toward it. No matter how much one walks, one never reaches the horizon. “What are utopias for?”—asked Birri, and continued, “For that, of course! They are for walking.” We invite the SDM research community to hold this imperfect, incomplete, yet hopeful map in their hands while walking toward 2028, amend and annotate it throughout the journey. We hope it will help us walk decidedly toward a future in which everyone can be cared for with SDM.

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Supplemental Material

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