

Qualitative Examination of Shared Decision-Making in Canada's Largest Health System: More Work to be Done

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Abstract

Background: Shared Decision-Making (SDM) is an inclusive approach where patients and providers work in partnership to make health care decisions that are grounded in clinical best practice and align with patient preferences and values. Despite a growing recognition that SDM can lead to improved outcomes and reductions in unnecessary health investigations, tensions exist between patient agency and a historically paternalistic model of health care. As an evolving ideology, the Research Team sought to better understand the current state, challenges, and implementation opportunities of SDM practices across the health system. **Methods:** This study used a cross-sectional quality improvement design utilizing semistructured interviews to gather information from focus group participants. Five open-ended, qualitative questions were used to generate discussion on the perceptions of SDM and its role in clinical appropriateness in a variety of clinical contexts in our health system. A total of 12 focus groups (n = 95 participants) representative of patients and families, leaders, physicians, and frontline clinicians were engaged in the study. **Results:** Through a consensus-based approach, study results identified 4 recommendations based on 4 themes: Time, Communication, System Design, and Clinical Appropriateness. **Conclusion:** There are no easy solutions to the challenges of enabling SDM; however, success will be dependent upon recognizing the importance of patient agency, while maintaining an inclusive and continuous stakeholder engagement with both patients and providers. Implementation of the 4 recommendations at the organizational level highlighted in this study can serve as a road map for other health care institutions and will require a gradual approach to transform the general principles of SDM into tangible solutions to meet the emerging needs at both the local and system level.

Keywords

Shared Decision-Making, patient agency, time, communication, system design, clinical appropriateness

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Introduction & Background

Shared decision-making is an inclusive systemic approach that respects the rights of patients and encourages them to be fully involved in decisions about their care (1). It is an interpersonal process where providers and patients collaborate to make decisions using best available evidence and patient preferences and lived experiences (2–4). Described as “the pinnacle of patient-centred care,” shared decision-making ensures that decisions reflect patients’ priorities and values (5). Shared decision-making is an evolving ideology that aims to resolve the tensions between patient agency and a health care provider’s responsibility to ensure that decisions are evidence-based and in the patient’s best interest. Today a majority of health care decisions follow a paternalistic model of health care and made exclusively by the practitioner (6). In recent years, shared decision-making has begun moving beyond research and theory toward policy and widespread clinical implementation (7). Although in shared decision-making, practitioners use their expertise to present and explain options to patients; patients use this information to develop preferences based on their priorities and values, and together patients and practitioners negotiate a final shared decision (6). Shared decision-making adoption has been driven by the recognition that a patient’s active role in their health care, improves outcomes and reduces unnecessary health care investigations and practice variations (8).

A key part of health care decision-making and clinical appropriateness is focused on clinical guidelines and recommendations. Although the patient-centric nature of clinical appropriateness is implied, the role of patient agency is often not directly addressed (9–12). Patient agency, influenced by a patients’ level of health literacy, speaks to a patients’ ability to directly impact the direction of their own health care needs (13). Evidence shows there are high rates of readmission and generally poorer outcomes when decisions are not jointly determined between individuals and their health care teams (14). Mulley et al. stated that this leads to preference misdiagnosis. Although health care systems are designed to address clinical misdiagnosis, they lack the tools to ensure “that patients receive the care they need, and no less, and the care they want, and no more” (p. 2) (14). When preference misdiagnosis is not addressed, patients become disengaged from their care, and the health care system is left treating and using resources to address problems not valued by patients and their families (14–17). When patients and their families feel empowered to discuss their treatment thoroughly with their health care professional, the decisions made are the most clinically appropriate for them.

Faced with finite health care resources, how do we balance clinical appropriateness and shared decision-making? Health care systems have often focused on designing an efficient care delivery model driven by clinical data and taking

patient agency for granted. This lack of patient voice in decision-making may have contributed to unnecessary tests and treatments wasting system resources (18). Ultimately if a health care system delivers care to a patient that is of no value, regardless of clinical evidence, it is wasted. The goal should always be to provide the care they need, and no less, and the care they want, and no more. But how do we achieve this?

To better understand the current state, challenges, and implementation opportunities to balance patient agency with provider autonomy in SDM and the role it plays in clinical appropriateness, the Research Team engaged with front-line health care providers, Health Advisory Council Members, and Patient and Family Advisors to answer these questions. To our knowledge, this is the first qualitative study to examine patient and health care staff perceptions on this topic across a provincial health care system. Our findings offer a road map to other health care organizations as they work to introduce more shared decision-making in their institutions.

Methods

Context

The health care system in Alberta serves a population of more than 4.3 million with 102,700 employees and 8,400 physicians. The health care system is organized into 5 geographic regions that are referred to as zones: South, Calgary, Central, Edmonton, and North and is supported by provincial programs such as strategic clinical networks, medical affairs, human resources, etc. Within the health care system, there are 12 Health Advisory Councils that bring the voices of Alberta communities to health care services. Additionally, Patient and Family Advisors are directly embedded in the health care system and share their lived experiences through participation on committees and projects.

Study Design

The study was a cross-sectional qualitative research study using semistructured interviews to gather information from focus group participants. Focus groups were organized virtually by videoconference or Skype from April to July 2019. Each 1-hour online session included 2 facilitators from the Research Team and focus group participants. Five open-ended questions were used to generate discussion (Please see Supplementary Materials). Inclusion criteria included patients 18 years of age and older, residents of Alberta, health care system staff, Health Advisory Council members, and Patient and Family Advisors. Exclusion criteria excluded participants with experiences/observations outside of the provincial health care system. The Quality Improvement Research Team consisted of male and female clinicians (not involved in direct patient care) and project

managers, whose experience in the organization ranged from 2 to over 10 years.

Participant Recruitment

An invitation to participate in the focus groups was distributed throughout the organization using various email distributions, newsletters, and frontline bulletin boards. The invitation directed interested participants to register through an online platform where input into various health care topics can be provided. Consent to participate was obtained through the online registration prior to the focus group.

Data Collection and Analysis

The focus group sessions were recorded using a voice recorder, or through Skype, and transcribed by NVivo Transcription Software (v12, QSR International). Using NVivo Qualitative Data Analysis Software, the Research Team used content analysis to systematically organize, analyze and code the recorded data. Initial open coding was completed individually by team members, resulting in a codebook. All files were then merged into one master file shared by the Research Team. The Research Team met and reviewed each code, and a consensus was achieved in the classification of data. Once corroborated by the Research Team, key themes were identified by one team member, and then validated through group consensus.

The Research Team endeavored to follow a rigorous qualitative analysis process. Through debriefing amongst the core Research Team, consistent checking of coding of themes and content analysis amongst the team, credibility was maintained. Transferability was addressed using field notes to ensure contextualization of themes across all stakeholder groups. Reflexivity was addressed through a description of the researchers' roles, gender, experience, and training as these variables may potentially impact interpretations of the data. Finally, validation of themes was completed through consultations with organizational leadership and Patient and Family Advisors.

Ethics

The University of Alberta Research Ethics Board approved (Ethics - Pro00089757).

Results

The invitation to participate in the focus groups generated 1,357 visits to the online platform from April to July 2019. In total, twelve focus groups were held across Alberta with 95 participants attending from across the province (Figure 1) and representing a variety of position types (Figure 2). Over half of the participants (57%) included frontline staff (n=17), physicians (n=3), and community

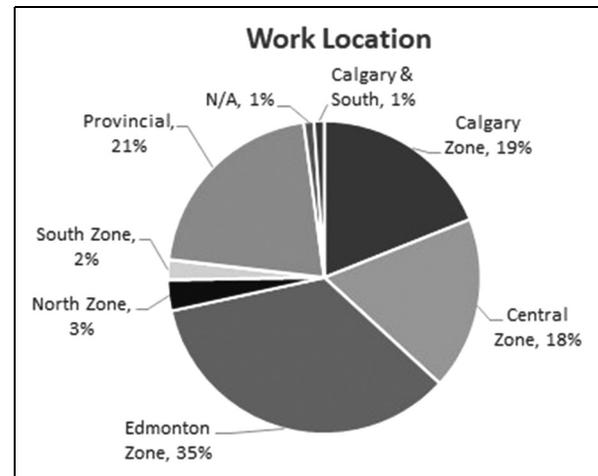


Figure 1. Participant work location.

representatives (n = 35) (*Health Advisory Council members, Patient and Family Advisors, and volunteers*). As the health system is provincial, it was important for generalizability to ensure all perspectives were represented from frontline staff to provincial & zone program staff. Given the size of the health authority, there may be regional differences in perspectives across the province. Participant's experience (Figure 3) was diverse with the majority between 0 and 5 years and over 20 years of practice.

Overall participants reported positive SDM experiences in their care or that of a family member, which was often attributed to a strong and trustworthy relationship with the provider. However, these positive experiences were often paired with reports of negative experiences citing inconsistent application of SDM as a significant factor throughout various settings in the health care system.

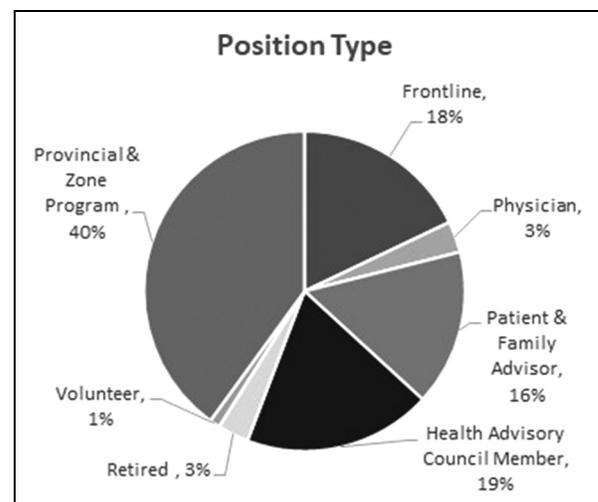


Figure 2. Participant position type.

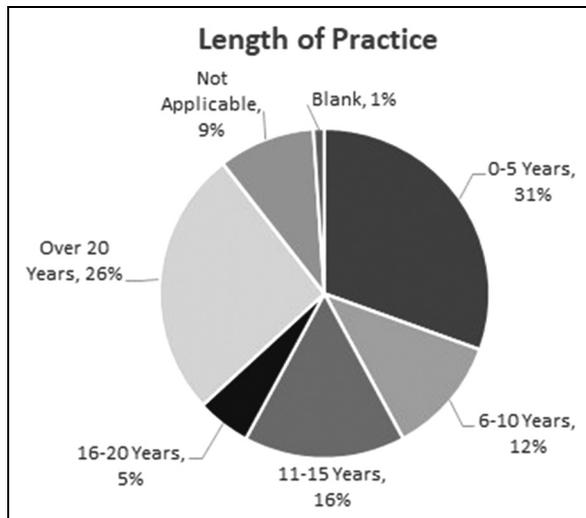


Figure 3. Participant length of practice.

I also see variation not just between individual providers but also between different areas and different services and units.(Focus Group 7)

The reporting of both a positive and negative SDM utilization was noted in both acute and nonacute care settings, including Palliative Care and Addictions and Mental Health.

Although participants reported an increased awareness of SDM among providers, a clear gap identified was without the consistent use of SDM practices, it is difficult to ensure the patient voice is heard so they can receive the care they need, and no less, and the care they want, and no more (14). This is critical to ensuring that patient agency is addressed. For example, one of the focus group participants recalled her experience:

When I was first diagnosed with cancer, I really didn't feel as though I was involved in any kind of shared decision-making at the time mainly because I wasn't educated as to what were the options for my treatment. No one really gave me any options. They just said this is what you're going to need and this what we are going to do, which turned out to be a lumpectomy and radiation. So then when I went through the lumpectomy the only time I actually got involved was because I had a nurse navigator who talked with me a lot, and I was able to ask her questions and so I said if this doesn't come back with a clear margin, I would rather go on to just having a mastectomy instead of another lumpectomy.(Focus Group 8)

This is just one of many examples shared by our focus group participants on the lack of inclusion of patient voice in SDM practices in our health care system and its unquestionable impact on patient agency.

Four key themes emerged through the analysis of our focus group's qualitative data with staff, Health Advisory Council members, and Patient and Family Advisors:

Communication, System Design, Clinical Appropriateness, and Time. These themes had elements of overlap and integration with other themes and the researchers noted a significant interconnectedness across each of the themes (Figure 4). The following sections will summarize the results of these 4 key themes.

Theme 1 Communication

As highlighted in Figure 4 above, the importance of communication was identified as central to all 4 themes. Participants reported that when their beliefs and values were both heard and respected, the interaction with the clinician became more meaningful. This communication enriched the relationship and, in turn, became a foundational aspect that supported the concept of SDM as a partnership between the patient and the provider. Participants noted a greater focus on relationship building between the patient and provider would ensure SDM is conducted within the context of trust and respect. One participant stated the importance of listening to their patients,

I am constantly reminding myself that when I'm in a patient visit with one of my patients to stop talking. You know I don't need to. I don't need to talk, I need to listen. My patient knows what's best for them. And I need to honor that, and I need to explore that.(Focus Group 4)

Conversely, lack of suitable communication skills and imposed time constraints were noted as barriers to

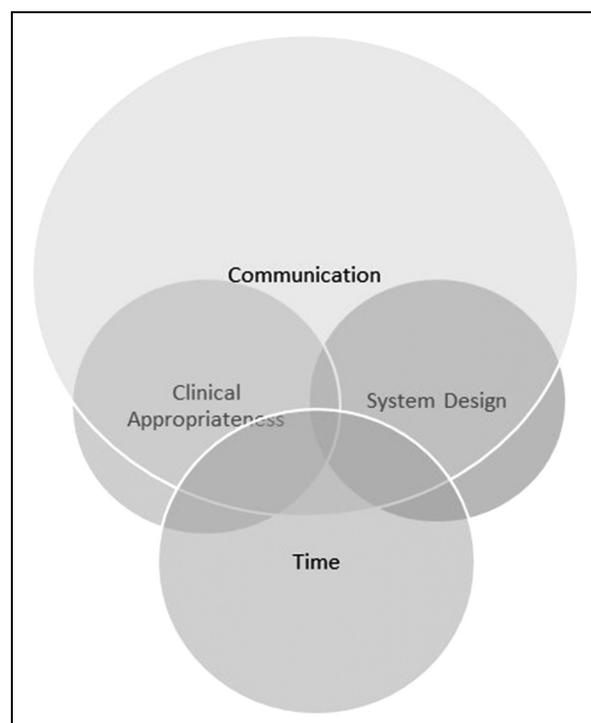


Figure 4. Interconnected themes.

constructive relationship building. Participants also identified that increased communication between health care providers and multidisciplinary care would support smoother transitions in care and SDM.

Theme 2 System Design

There was consensus that a system-wide approach was required to support patients and health care professionals through health care provider skill development, improved patient health literacy, and general SDM awareness from both patients and providers. One participant explained,

I think there are still people that access a system ready to be a passive participant and let the health care provider just be the pilot tell me where to go and tell me what to do so to speak.(Focus Group 6)

Consistent across all discussions with participants was better provider communication skills and education are essential to encourage more SDM in the health care system. Of note, was the differing generational and cultural approaches used when interacting with the health care team. For example, it was identified that increased implementation of SDM requires an awareness of these differences and the development of support tools to address them. Additionally, changing technology has allowed for greater access to health care information, including patient access to lab and imaging reports. Therefore, broader implementation of SDM needs to foster this utilization of technology with tools that support health literacy among patients and families. Undergirding this, participants identified the need for a flexible system, supported by clear and practical policies that include the voice of the patient, to help support SDM while adapting to the unique needs of the system.

Theme 3 Clinical Appropriateness

Overall, participants expressed difficulty in understanding the concept of clinical appropriateness. However, once clear on the concept, participants indicated that SDM and clinical appropriateness are closely linked, and noted the importance of being good stewards of the public dollar by using resources appropriately.

Participants identified that SDM has a role in allowing providers to understand patients' values so that as care is discussed, what is important to patients is considered in determining the right treatment at the right time by the right provider (10). It was identified that if patients feel heard, they will be more receptive to considering that the treatment they are asking for may not be the most appropriate for them at that time.

I need to know why. That's one of the things I need when I'm having those conversations. So when those needs are met, I'm more receptive to hearing why this may not be the right care or the right way to go.(Focus Group 2)

Participants also indicated that creating a trusting and strong relationship between patient and provider fosters clinical appropriateness. Conversely, it was noted that there can be conflicts in knowledge and values between the provider and patient in determining what is appropriate. Providers may make value-based judgments on what treatment would be appropriate for the patient without fully considering the patient's values, and patients and families may not consider the clinical judgment or knowledge of the provider further influencing how decisions are made and affecting the patient-provider relationship.

If you're looking at who's making the decision about whether what is the right care what is the right time, that has to involve the patient and the expertise of the provider, as well. So for me, it speaks to, you know, clinicians doing their duty of care but the patient still has the right to choose.(Focus Group 5)

Theme 4 Time

A recurring theme throughout all the focus group discussions was that patients require time to properly make decisions and establish a relationship with their health care team.

We don't really know because we haven't had time to even think about the possibilities of what it is you're asking.(Focus Group 2)

Patients reported that they often feel rushed and need time to understand all the choices and information they are being presented with, as well as time to clarify, ask questions, and consult family or friends.

I wish I had been informed a little bit more about the slow-growing nature of prostate cancer and about the time I actually had to make the decision.(Focus Group 9)

Discussion

The results of the twelve focus groups (n = 95) held across Alberta identified some considerable challenges and implementation opportunities for SDM in the province. SDM was highlighted to play a key role in clinical appropriateness. Participants conveyed both positive and negative experiences, notably due to significant reports of inconsistency in SDM practices throughout the health care system. The key facilitator of a positive SDM experience was the presence of a solid relationship with the health care team, built on communication and trust. Better communication within health care teams encourages providers to communicate along the continuum of care and connecting the patients care episodes led to better experiences. Engaging patients, within an environment of trust and respect, was

foundational to allowing robust SDM to occur. This is supported by Ward et al. that found that the shifting patterns in doctor–patient relationships are becoming more of the challenge for health care providers and that trust and communication influence both patient satisfaction and perceived quality of health care services (19).

Furthermore, participants stated that clear organizational definitions, policies, and procedures and a robust communication strategy, supported by provider and patient awareness and education, are needed to support consistent SDM. Investing time upfront by implementing the essential elements of SDM will pay significant dividends in the way of quality, experience, and time/cost efficiencies was a sentiment many participants expressed. The interaction between clinical appropriateness and SDM, although agreed to be an essential element, needs to more clearly understood through both public and staff awareness but there is also a paucity of literature discussing this tension between clinical appropriateness and SDM in health care. Recognizing that conflicts between provider values and knowledge and patient values in determining what is appropriate; providers sometimes make value-based judgments on what treatment would be appropriate for the patient (20).

The identified themes corroborated from our findings were consistent with those outlined by other authors examining the barriers and facilitators of SDM (15,21). Of note, Hofstede et al. highlighted the need for a robust organizational context to support SDM. Their recommendations included addressing logistical issues (eg, waiting lists, visit length) and external factors (eg, reimbursement) as barriers that need to be overcome through organizational and policy changes (21). This is further validated by a recent ethnographic study by Manhas et al. in Alberta, Canada who aimed to understand patient and provider perceptions of SDM in community rehabilitation, particularly the barriers and facilitators to SDM and concluded that SDM centered on 2 extremes of getting patient buy-in and aligning expectations between providers and patients (20).

As mentioned in the introduction, the authors allude to the notion that patient agency is often in conflict with institutional structures and external factors, and patients often lack the supports to advocate for their values when engaging in SDM (1,8,22). Many of the focus group participants implied this when they highlighted the need to address differing views within their context and the importance of greater access to health information. In this novel, emerging era of increasing accessibility to online health data, through the creation of new electronic medical records patients will have more access than ever before to their personal information and knowledge of the management of their care with (23). Therefore, it will be even more essential that organizational and system structures be in place to allow patients to advocate for their values, agency, and engage in SDM (24).

As evidenced by our themes on SDM, when patient agency is not addressed, an unintended consequence is

that patients become disengaged from their care, and the health care system is left treating and using resources to address problems not valued by patients and their families (9,14–17). The emerging SDM themes from our study on the importance of Time, Communication, System Design, and Clinical Appropriateness suggest that when patients and their families felt that providers had good communication skills and adequate time they were empowered to discuss their treatment thoroughly with their health care professional. As a result, patients will determine what is most clinically appropriate for them, receiving the care they need, and no less, and the care they want, and no more (14).

Recommendations

Several organizational level recommendations have emerged regarding the current state of SDM in the health care system as well as ways to facilitate SDM in the future. Through a consensus-based approach, our study results revealed 4 recommendations based on the 4 themes: Communication, System Design, Clinical Appropriateness, and Time (Table 1).

The generalizability of implementing these recommendations specific to SDM should include broad-based engagement with participation from Patient & Family Advisors, frontline clinical staff, and key organizational leaders to help develop practical solutions and encourage opportunities for SDM implementation at the site, department, and unit level. As these recommendations may have impacts across the health system at many levels, it is recommended that a gradual approach that allows for the incorporation of SDM into workflows may be needed in consultation and engagement with frontline staff, administration, and leadership. Regular monitoring of progress towards more SDM should be reported broadly and be a key commitment by the organization. Our findings are not exhaustive and offer a road map to other health care organizations as they work to introduce more shared decision-making in their institutions.

Limitations

This study is subject to some identified limitations. Only 3 physicians participated in the focus groups, thus limiting access to data and generalizability to physician groups across Alberta. The recruitment method focused on using email distribution and electronic newsletters, which may have impacted physician recruitment; posters were printed and put into breakrooms but those that do not use email regularly could have been missed. Patient participants were part of the health care system engagement teams thus had a biased perspective compared to the general public. Further, the study used a cross-sectional qualitative research study and included a convenience nonprobability sample which may have resulted in sampling and selection bias of participants. Also, all focus group sessions were held virtually, which

Table 1. Key Findings & Recommendations.

Theme	Key findings	Examples of qualitative quotes from focus group participants (N= 95)	Organizational level recommendation
Communication	<ul style="list-style-type: none"> There is a lack of communication between patients and providers and within health care teams 	<p><i>When my husband was injured, I was not familiar with the medical profession and dealing with hospitals, I was extremely stressed not knowing at first if he was going to survive and then not knowing what the outcome was going to be. So there was a lot of information that I needed, but I wasn't clear on who I can get that information from.(Focus Group 8)</i></p>	Enabling SDM requires fostering communication within health care teams & across the patient journey as well as between providers and patients.
System Design	<ul style="list-style-type: none"> Not proactive and flexible Lacks provider education and tools to build skills Insufficient time to build relationships and trust 	<p><i>This shared decision-making process does embody a lot of soft skills. So when you do ask someone about what they want for their treatment goals it sometimes takes practice to be able to read between the lines of what they're saying. And it makes me wonder like how are these things being taught at the lower level? How are students or interns or residents being taught what this process involves?(Focus Group 11)</i></p>	The organization needs to create policies and procedures that are proactive and flexible, that provide education and tools on the essential of SDM, while allowing for space to build relationships & trust for the patient voice and values to be understood
Clinical Appropriateness	<ul style="list-style-type: none"> There was difficulty understanding the concept of appropriateness Patient values have a role in determining appropriateness through SDM There are conflicts between provider values and knowledge and the patient values in determining what is appropriate 	<p><i>As a provider, it would be highly inappropriate for me to work on walking when we don't have trunk control or an ability to mobilize in bed and sit independently, but it's very harmful to the relationship if I just tell the patient that's not appropriate. That's not the approach I need to take. So we need to find that common ground. You know, I certainly have to acknowledge what the patient is telling me that is important to them.(Focus Group 6)</i></p>	Clinical appropriateness needs to be more clearly defined and understood through both public and staff awareness
Time	<ul style="list-style-type: none"> Lack of time for patients to understand and consider their options Lack of time to consult with family and friends Lack of time to establish a trusting relationship Lack of time for providers to engage in SDM 	<p><i>And I think sometimes it's hard for us as providers to take the time upfront to do maybe what needs to happen up front, trusting that it will save time farther down the line when you have a waitlist of patients wanting to see you. But I think it's about working with our clinicians and helping them develop the skills and a willingness to take that time to develop that trusting relationship with their families, to really get to shared decision-making. And I think as a family member or parent, it's also about knowing before I go in what the expectations are for me as a parent, what decisions can I make?(Focus Group 5)</i></p>	A system that enables SDM needs to allow time for patients to be fully informed, make decisions that align with their values and understanding, and allow for providers and patients to build trust.

may have influenced the rapport developed between the researcher and participants and potentially affected the richness of data obtained. In addition, participants may have had some degree of recall bias, recalling either only very positive or very negative experiences during the focus group sessions.

Conclusions

Optimal SDM has been demonstrated in both our findings and the presented literature to lead to overall better patient outcomes as well as more effective utilization of finite health care resources. Our study has identified that although

many current state challenges exist in the health care system, utilization of 4 generalizable recommendations based on the emerging themes of Time, Communication, System Design, and a well-defined and understood the concept of Clinical Appropriateness can be applied to overcome many of the barriers. These recommendations can serve as a road map for other health care organizations and may be applied in any health care context. There are no fast and easy solutions to the challenges of facilitating and enabling SDM; however, success will be dependent upon recognizing the importance of patient agency, while maintaining a holistic, inclusive, and continuous stakeholder engagement with both patients and providers. Our findings suggest that upfront investment in strategies that address overlapping elements across the 4 themes will pay significant dividends in the way of quality, experience, and time/cost efficiencies in any health care setting.

Authors' Note

Ethics approval to report this case was obtained from the University of Alberta Research Ethics Board (Ethics - Pro00089757). Written informed consent was obtained from participants for their anonymized information to be published in this article.

Declaration of Conflicting Interests

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Supplemental Material

Supplemental material for this article is available online.

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