Addressing disparities in patients’ opportunities for and competencies in shared decision making

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In this issue of BMJ Quality & Safety, Birkeland and colleagues\(^1\) conducted an online experiment where 6756 male healthcare users in Denmark were randomised to view 1 of 30 case vignettes of possible scenarios they may encounter when making a decision about prostate cancer screening. In this study, 30 case vignettes were created that varied by level of patient involvement in making the decision, screening choice and downstream cancer outcomes.\(^1\) Despite using hypothetical scenarios and limiting the sample to men, this study yielded important insights into the impact of shared decision making (SDM) on peoples’ reports of satisfaction with their care.\(^1\) Birkeland and colleagues\(^1\) found that participants were generally more satisfied with scenarios where the doctor was in favour of PSA testing, but greatest levels of satisfaction with their healthcare were observed when there was SDM, use of a decision aid, and dialogue with their doctor. Interestingly, this remained the case even in scenarios where patients had poor outcomes, suggesting that ownership of the decision to screen is important in acceptance of poor clinical outcomes.\(^1\) These findings suggest that a high-quality SDM process, supported by the use of decision aids, may be protective against regret for patients who experience poor outcomes following a decision. More research with patients facing difficult, preference-sensitive healthcare decisions is needed to explore this hypothesis.

Birkeland and colleagues’\(^3\) discussion highlights the prior mixed research regarding associations between SDM and patient satisfaction. Crucially, they suggest that one possible explanation for the mixed findings may have been the ceiling effects for patient satisfaction; most patients tend to be satisfied with their care even if no SDM is involved. This finding aligns with previous research that found that while patients desired some level of involvement in decision making, they did not expect SDM with their doctor and may not be aware of opportunities for SDM.\(^3\) As providers move towards a patient-centred model of care, how do we engage patients in SDM and make SDM normative for both patients and providers in order to ensure that expectations between patient and provider in the medical encounter are aligned? Some patients may not expect SDM from their provider, may not be aware that SDM has benefits for them beyond usual care, or may not have the skills or competencies to confidently initiate or engage in SDM with their provider.

Some scholars have also expressed concern that SDM may exacerbate health disparities experienced by socially disadvantaged groups, which include characteristics such as having limited education, being uninsured, being female, having an immigrant status, being non-white, having limited English proficiency and having low literacy.\(^2\) Although all patients could benefit from more SDM with their providers, socially disadvantaged groups may be disproportionately impacted if they have underdeveloped skills or competencies or limited opportunities to effectively engage in SDM with their provider, and hence may experience health disparities such as poor quality of care or lower patient satisfaction.\(^5\) Indeed, Towle et al\(^7\) emphasised that patients should possess certain skills for SDM so that the responsibility for initiating SDM does not rest with the provider alone. Greater patient involvement also means greater responsibility for the patient to understand information and to participate in decision making.
While there are a number of studies on building SDM competency among providers and use of decision aids to facilitate the SDM process, there appear to be fewer interventions or tools that enhance similar SDM competencies in patients. Towle et al, for instance, have begun to define a list of competencies for patients that may be useful in SDM, which includes skills such as clear articulation of health problems and expectations, communication with the provider and ability to evaluate information. In addition, other qualities or skills such as communication efficacy (ie, the ability in one’s ability to communicate with a provider about a health issue) and numeracy skills (ie, the ability to comprehend numerical information) can also affect the degree of patient involvement in the SDM process and risk comprehension. An equally important competency is the ability to minimise bias in decision making. An important finding in Birkeland and colleagues’ paper is that participants were less satisfied with scenarios where a healthcare provider nudged them away from screening. Two factors may explain this finding: (1) conventional wisdom that early detection of cancer is always best and has few if any downsides or risks; and (2) action bias, where taking any action is preferred over what is seen as doing nothing. Future research can focus on identifying the necessary skills and competencies for patients to effectively engage in SDM and consider educational components for patients that could be incorporated in existing interventions to overcome disparities in engaging in SDM.

One way of instilling SDM competencies in patients and overcoming disparities in ability to engage in SDM is through the use of educational narratives, which can take the form of personal testimonials or entertainment narratives (eg, telenovelas and soap operas). These may be disseminated to patients as part of a patient decision aid prior to their SDM visit with the provider (eg, as an educational video in a web-based patient decision aid). The International Patient Decision Aids Standards Collaboration recently conducted a series of reviews to evaluate the utility of including patient narratives in patient decision aids. They concluded that there should not be a blanket recommendation for patient narratives to be included in patient decision aids due to mixed findings on their effectiveness and the potential to bias patients’ judgement and decision making. However, the review acknowledged that narratives can be a powerful tool to communicate information and to address issues of health literacy. Narrative persuasion research has argued that narratives can provide conversational scripts for the audience to engage in interpersonal discussion by showing characters in the story successfully modelling the behaviour. For instance, a study by Moyer-Gusé et al found that when audiences identified with the character in the narrative that had a conversation about safe sex behaviour, they had greater intentions to engage in safe sex discussions. Similarly, a narrative with a character that effectively engages in an SDM discussion with their provider can provide conversational scripts for the audience to use in their own SDM encounters, hence increasing communication efficacy. In addition, the use of narratives is proposed to be particularly effective compared with other message types (eg, didactic messages) for populations that have low literacy.

Current SDM principles and patient decision aids are based on the rational model of choice behaviour. In the rational model of choice behaviour, the decision maker engages in cognitive processes such as considering the different choices, weighing risk and benefits and considering probabilities of a certain action occurring. There is also an implicit assumption that interventions

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SDM, shared decision making.
or decision aids designed for a general population are able to address the needs of cultural minorities, and there is a lack of emphasis on understanding the SDM needs and preferences of cultural minorities.23 This may exacerbate health disparities experienced by cultural minorities by limiting their opportunities or willingness to engage in SDM with their providers if the SDM process is not culturally sensitive or if the patient decision aids provided to them are not culturally relevant or informed. Indeed, existing research suggests that current SDM principles may not fully reflect the perspectives of cultural minorities. For instance, a study conducted with African–American patients found that SDM was conceptualised in different ways and that African–Americans prioritised certain aspects of the SDM process, such as telling their story and feeling heard, as well as information sharing by both doctor and patient.24 A systematic review of SDM for cancer care among ethnic minorities in the USA found that factors such as level of acculturation and fatalistic beliefs about cancer (based on spiritual and cultural beliefs) impacted decision making.25 In addition, family or community members were important in the decision-making process, leading the authors to suggest expanding the traditional SDM model beyond patient and provider.25 These studies highlight a space for future research to examine whether current SDM principles apply to cultural minorities, particularly understudied groups such as Asian Americans in the USA, and how their understanding of SDM, attitudes towards SDM, and preferences for SDM differs based on their cultural context. Additionally, reviews of patient decision aids also suggest that few are culturally targeted or appropriate.26 Along with an understanding of how minority populations view SDM, patient decision aids can be designed to be culturally targeted or appropriate while reflecting the norms, values, preferences and needs of minority populations.23 27 Please see table 1 for a summary of the disparities in patients’ engagement in and use of SDM and potential solutions to address these disparities.

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REFERENCES


