Shared Decision Making in Cancer Care

Does One Size Fit All?

Sarah T. Hawley, PhD, MPH; Reshma Jagsi, MD, DPhil

Shared decision making (SDM) has been identified as a key element in patient-centered care, particularly within the field of oncology. Shared decision making has been associated with improved patient knowledge about treatment options and increased satisfaction with the overall care experience. Still, important questions remain regarding the impact of SDM on outcomes in patients who vary in many ways, including their type of cancer diagnosis, sociodemographic characteristics, and preferences for involvement in decision making.

In this issue of *JAMA Oncology*, a thought-provoking contribution from Kehl and colleagues enriches the literature on the merits of SDM by evaluating the association between SDM and 2 important patient-reported outcomes in cancer care. Using data from the Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) Study, a large population-based survey of patients with lung and/or colorectal cancer between 2003 and 2005, the authors assessed the association between patient-reported actual and preferred role in treatment decision making and perceptions of quality of care and communication with their physicians. The authors found that when patients reported engaging in shared decisions (relative to physician-driven decisions), they more often reported excellent quality care and more positively rated their physicians’ communication. The focus on these 2 patient-reported outcomes represents a strength of this study because these outcomes have not been well studied in the SDM literature. Another novel aspect was the comparison of how patients prefer treatment decisions to be made with how their cancer treatment decisions were actually made. The study found that the associations between having experienced a shared decision and positive appraisals of quality and communication held regardless of the patient’s preferred role in the decision-making process.

One challenge highlighted in the article by Kehl et al is that of measuring patient involvement in decision making. To measure both preferred and actual involvement, the authors used the Control Preferences Scale, a 5-point scale that evaluates how medical decisions are made (1, by the patient alone; 2, by the patient with physician input; 3, fully shared; 4, by the physician alone; 5, not involved in decisions).
physician with patient input; and 5, by the physician alone). As has been done in prior work, the authors collapsed the scale into 3 groups for analysis: “patient controlled” (categories 1-2), “shared” (category 3), and “physician controlled” (categories 4-5). Most patients desired a shared (58%) or patient-controlled (36%) decision, while only 6% reported preferring a physician-controlled decision. Of these 6%, at least some would have fallen into category 4 (still desiring some input). The degree to which patients can fully distinguish a “shared” decision from one where the physician makes the decision with patient input (category 4) or where the patient makes the decision with physician input (category 2) is not clear.

We find it unsurprising that even patients who preferred a physician-controlled decision rated the physician communication outcome highest when the actual decision-making process was more shared, as the individual items that constitute the communication measure described elements most likely to be absent when the actual decision is not shared. More compelling is the association found between SDM and patient appraisal of excellent quality of care. It is intriguing that this association remained even when controlling for preferred role. Kehl and colleagues3 confirm from this finding that it is important to promote SDM, even among patients who may seek less active roles. Yet these results are in some contrast to prior work that has suggested that it is the match between patients’ preferred and actual involvement that contributes to greater satisfaction with care.5,6 These conflicting results underscore the need for further work to better quantify and link measures of SDM to patient appraisal of care.

As noted by the Kehl and colleagues,3 it is likely that some patients want to be involved in decisions but also want their physicians to provide some type of treatment direction or recommendation. This possibility raises questions regarding what physicians should do with patients who express a preference against decision involvement. We suspect very few patients truly endorsed an underlying preference for little or no involvement (category 5) and that even within the 6% preferring a physician-controlled decision, most wished for their opinion to be considered. Nevertheless, physicians may occasionally encounter patients who truly desire to play a minimal role in the decision-making process, and we do not believe the current study results should be taken to suggest that such patients should be coerced into participating more than truly desired. A more directive decision-making process might be a more appropriate way to demonstrate respect for such patients’ preferences.

An additional layer of complexity not addressed in the article by Kehl et al3 relates to the fact that patients may have very different preferences for the degree of involvement in decisions that vary in nature, magnitude, and scope. If patients rated their preference for decision involvement considering most routine medical decisions while their recollection of cancer treatment decisions was focused on particularly serious decisions, this situation might partly explain why even the few patients who expressed a preference for physician-controlled decisions rated the quality of care higher when decisions were shared.

In part because of the complexities of measuring patient preferences, patient involvement, and patient-reported outcomes in the context of cancer care, we believe that further work is necessary to build on this important contribution from Kehl et al.3 The authors are to be commended for evaluating SDM in patients with cancer types less frequently studied than breast cancer. Further research should seek to extend these insights still further by evaluating variation in the desire for and experience of decision involvement by other meaningful patient characteristics, such as age, educational attainment, and sex. Further research is also necessary to link patient-reported appraisals of care to actual receipt of services; it would be informative to know what tests and treatments patients who rated their care as “excellent” actually received. If we are to eventually incorporate patient-reported outcomes into quality metrics,7,8 we must understand how these outcomes associate with health care utilization.

In conclusion, while the important study from Kehl and colleagues3 confirms that most patients want a voice in their care, we believe that there remains much need to improve our understanding so that physicians may tailor treatment discussions to the different types of patients they encounter. Shared decision making is a key element of high-quality care, but this does not mean that “one size fits all.” Individualizing the approach to decision making in an evidence-based fashion will allow us to maximize the respect we accord to the patients in our care. We appreciate the contributions of Kehl et al in providing critical evidence to that end.