Kidney Medicine

When Shared Decision Making Fails: Decisional Regret in Kidney Disease

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Shared decision making in health care occurs when clinicians provide patients with information on the best available treatment evidence; support patients in their deliberation of treatment options; and partner with patients to make an informed choice that aligns with their goals and values.[1] According to decision theory, decisional regret occurs when an individual believes that a better outcome would have been achieved had an alternate decision been made.[2] Regret increases when potentially useful information about the best course of action arrives after the fact, or perhaps never at all. In essence, decisional regret is what patients may experience when shared decision making fails.

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The importance of shared decision making has most frequently been described in nephrology in the context of beginning dialysis. More recently, decisional regret related to dialysis has emerged as a potential consequence of failed shared decision making and a focus of scholarly inquiry on its own.[3-5] In this issue of *Kidney Medicine*, Pawar et al (Pawar A, Thorsteindotir B, Whitman S, et al. Decisional regret surrounding dialysis initiation: a comparative analysis. *Kidney Med*. 2023, in press) apply a unique study design to further expand on our knowledge of decisional regret in dialysis.

Using a sequential, explanatory mixed-methods (qualitative and quantitative) design, Pawar et al deeply explore causes of decisional regret among participants receiving hemodialysis or peritoneal dialysis at one academic medical center. In the study's initial, quantitative phase, 78 participants were surveyed using a validated measure of decisional regret. This step informed the purposive sampling that occurred during the study's subsequent qualitative phase, during which 21 participants, selected from those who reported the highest and lowest levels of decisional regret, were interviewed. To synthesize and report themes and subthemes from participant interviews, the authors applied grounded theory, a qualitative data analysis method by which theoretical insights are inductively derived from the data.[6] Participants reporting lower decisional regret generally reported healthier coping strategies, including positive reframing, acceptance, goal setting, and cultivating healthy distractions. Most importantly, these were individuals for whom dialysis allowed the continued presence of pleasurable life activities and supportive relationships. Those participants who reported higher decisional regret strongly emphasized feeling underprepared because of a lack of knowledge related to potential increases in symptom burden and a loss of independence.

The study performed by Pawar et al has a number of strengths. By design, qualitative analyses are not intended to detect statistically significant differences in the frequencies of quantitative variables or participant characteristics. Often, these studies do not contain a prespecified hypothesis. Rather, qualitative and mixed-methods studies use interviews, observations, and free-text analysis to deepen our understanding of the causes and consequences of emotions and behaviors in ways that quantitative analyses cannot.[7] As such, the study design by Pawar et al is the most appropriate one to deeply explore the causes of such complex psychological constructs as regret. Additional strengths include that survey administration techniques were rigorous and involved on-site assistance for participants who needed it. Though there are no published cutoff scores to determine what valid levels of high versus low decisional regret are in dialysis, the authors' intentional choice to purposefully interview those who scored at the extremes of decisional regret allows the reader to understand factors involved not only in failed shared decision making but successful decision making as well.

Pawar et al used the decisional regret scale to measure regret related to dialysis.[8] This 5-item measure, originally validated among groups of patients making decisions related to postmenopausal hormone replacement therapy, breast cancer treatment, and prostate cancer therapy, was developed using an iterative process of discussions among decision scientists and clinical providers, pilot testing, and further measure refinement. The scale has good internal consistency (Cronbach alpha = 0.81-0.92) and moderate convergent validity with other related measures (decision satisfaction, $r = -0.40$ to -0.60; decisional conflict, $r = 0.31$-0.52). The final scale is parsimonious and includes aspects known in the literature to constitute an informed decision, including anticipated regret. It remains unclear whether the decisional regret scale's lack of validation in patients receiving dialysis should limit its use in kidney disease research. Because dialysis involves a loss of independence that is specifically linked to a physical machine, it may be that decisional regret in the context of kidney failure is unique and warrants the development of a modified scale.

Some other aspects of the study also merit further discussion. Of the 126 participants approached, only 78 agreed to participate in the survey. Though the reasons for this slightly lower participation rate are not described, it may be that those approached were uncomfortable or unprepared to reflect on their dialysis choice. Evidence supports that many patients receiving dialysis are unaware

that beginning dialysis was a choice in the first place.[9] Because most participants interviewed reported lower decisional regret, the study may have been biased to exclude those for whom a shared decision-making intervention related to dialysis would have been most beneficial.

Because the quantitative portion of the study does not contain a sample size powered to test for statistically significant differences between groups (occasionally done in other mixed-methods studies), care must be taken to avoid making robust conclusions related to these results. However, some quantitative findings may be worthy of future inquiry. More participants reporting low decisional regret were receiving home dialysis. Furthermore, the median age of participants reporting high decisional regret was 17 years younger than those with low regret. Indeed, factors that influence decision making are known to change with age.[10] These potential differences between groups, in addition to potential differences related to the validated measures of illness intrusiveness and self-rated health used in this study, should be proven and studied in future work.

Regret is a nearly unavoidable part of our lived experience as human beings. Frameworks used in healthcare decision-making emphasize that decisional regret involves complex interplay of previous health experiences, relationships with peers who may have had to make similar decisions, an individual's cognitive representations of a health threat, regret aversion, and risk perception.[2,11] Within the context of patients receiving dialysis, whether and how factors such as dialysis vintage, cognitive function, caregiver support, psychological affect, kidney disease-specific knowledge, prognostic awareness related to kidney transplant status and dialysis risk, and perceptions of therapeutic alliance with one's nephrologist may affect decisional regret may be interesting to explore. If modifiable, these factors may support adaptive coping strategies and serve as targets in an intervention to support best practices in shared decision making in dialysis.

Choosing dialysis can be both life-changing and life-limiting. We must provide our patients with honest, transparent prognostic information related to treatment choices, foster a supportive environment to support deliberation of these choices, and elicit their life goals such that decisional regret is minimized and high-quality shared decision making is achieved.

ARTICLE INFORMATION

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