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Unexpected Outcomes of Measuring Decision Regret: Using a Breast Cancer Decision-Making Case Example

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Abstract

Shared decision making can help patients feel supported and empowered when deciding between health care options. Decision regret can be a meaningful measure of the quality of that encounter.

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However, in a patient-engaged research study examining shared decision making for breast cancer surgery, decision regret was a difficult construct to assess, and asking questions about decision regret caused the patient to experience that emotion upon reflection. In this article, we consider the complexity of decision regret, and discuss the difficulty of measuring that emotion through existing instruments. We call for clarity in definitions of decision regret and offer suggestions for developing a set of questions that can capture regret in a more meaningful way.

Shared decision making is a process during which clinicians engage patients and families in weighing their care choices [1, 2, 3]. It can help patients feel supported and empowered as they consider their options and how those options align with their values, needs, expectations, and risk tolerance [4, 5, 6]. One way we can measure decision quality, defined as informed, preference-consistent decision-making [7], is by asking whether patients regret their choice or the decision-making process over time [6, 8–9, 12, 13]. However, as we discovered in a patient-engaged research study examining shared decision making for breast cancer surgery, decision regret can be a difficult construct to assess [8, 9]. When a patient is newly-diagnosed with breast cancer, they are often faced with multiple reasonable care options and no clear best choice [10, 11]. This is especially true with early breast cancer, when women are more likely to face the decision between breast-conserving surgery (BCS) and mastectomy. Using our breast-cancer decision-making study as a case example of the limitations of existing measures of decision regret, in this paper we will describe decision regret and call for more clarity on its measurement and impact, building on work from others who have evaluated this concept and its multiple layers.

1. Defining Decision Regret

Decision regret can be broadly defined as a retrospective emotion experienced when evaluating the outcome of a decision, but lived experiences of the emotion can be multifaceted and shifting, making it a difficult concept to pin down. There are various types of decision regret, which experts typically categorize into three groups [13–16]. Some people experience *process regret*, as they blame themselves for a perceived failure to ask the right questions, seek out information or thoroughly explore options during decision-making [13–16]. This type of regret can occur regardless of how much time and effort was put into the decision-making process. Others feel *option regret*, doubting the decision option they chose, even if they feel they went through a thorough decision-making process [13–16]. Sometimes there are several imperfect options, such that even the best process leads to dissatisfaction or regret about a choice. Some experience *outcome regret* if they are dissatisfied with the results of the decision made [13, 15, 16]. This type of regret can emerge or intensify over time as outcomes become known.

Regret may occur at any point along the decision-making course, and may fluctuate as outcomes change. The desire to minimize regret has an important role in how people weigh their options and make decisions [17–20]. Zeelenberg and Pieters developed a theory of regret regulation to address this functional nature of regret and synthesize regret literature across a range of fields and purposes [14]. They assert that to understand experiences of decision regret, one must first consider how patients attempt to avoid or mitigate the

possibility of regret during decision-making. Joseph-Williams and colleagues, on the other hand, caution that Zeelenberg and Pieters' theory presumes that regret will remain static [13], while evidence suggests that regret is not typically a static experience felt at one point in time [17]. In a systematic review of decision regret measurement tools used in a healthcare context, Joseph-Williams et al. proposed a framework as an extension of the theory of regret regulation to evaluate these research instruments in a way that accounts for the multiple, possibly co-existing types of regret and their temporal nature [13].

2. Measuring Decision Regret

What Joseph-Williams and colleagues found when applying their framework to existing regret measurement instruments, including the validated decision regret scale [12] we used in our breast cancer decision-making study [8, 9], is that many measures fail to capture the various types of decision regret and how they interact and shift, instead focusing on one type of regret or one momentary experience of regret [13]. They also found that existing measures assume regret to be a wholly negative emotion and fail to account for the potentially positive outcomes of experiencing regret, such as evaluating one's decision making process to avoid future experiences of regret. Outcomes of regret, or how a patient reacts to that emotion over time, are potentially useful variables in understanding how they feel about the decision. Moreover, the majority of measures they assessed had some level of mismatch between stated definition of what they were trying to measure and the items in the scale used to make that measurement. This suggests that clear and consistent definitions of constructs could inform the design of a stronger measure of decision regret. Further, the difficulty these tools have in defining and capturing such an unstable concept suggests that, in the patient's experience, too, the boundaries between different types of regret are porous and shifting and may not be well understood by the patient herself, as we found in patients' responses to questions about regret in our own study (Table 1).

While evaluating the impact of two conversation aids on decision quality among women with early breast cancer, we used a validated measure of decision regret to ask patients how they felt about their choice of either mastectomy or BCS [9, 12]. Patient associates who previously had breast cancer, along with research staff, facilitated recruitment and administered baseline and follow-up assessments, collecting data on regret at three points post-surgery: one week, twelve weeks, and one year. When administering the surveys, they received unexpected responses that suggested that experiences of regret were much more complicated than the quantitative measure could ascertain (Table 1). The mean regret score at one week post surgery was 10.6 (SD 13.6). The mean regret score at 12 weeks post surgery was 9.5 (SD 14.5). The mean regret score at 1 year post surgery was 7.1 (SD 12.4). Regardless of numeric score, for some patients, answering questions about decision regret led them to reflect on their choices and their feelings of regret increased during the process of reflection.

The porousness and dynamic nature of these experiences of regret make them difficult to quantify—one may experience any or all of the types of regret at any point during or after the decision-making process, and the type and strength of regret can fluctuate. Standards for how to measure a good quality decision need to account for how a patient feels over

time—when the patient has just made a decision, after having time to reflect on that decision, after outcomes had time to play out, and so forth. Currently, there is no standard for when or how often to measure decision regret, and no standard for whether a baseline measurement of anticipated regret or regret tolerance should be taken. In our study [8, 9], we asked about decision regret three times (1 week post-surgery, 12 weeks post-surgery, and 1 year post-surgery). At 12 weeks post-surgery, we also interviewed women about their experiences. In regression analyses adjusted for patient and clinician variables, the use of a conversation aid with pictures led to lower decision regret at one week post-surgery, but had no effect on decision regret at 12 weeks and 1 year post-surgery in comparison to usual care. The text-only conversation aid led to no differences in decision regret. Regret may be one of the most widely studied aspects of decision quality, but assessment must occur longitudinally to capture the breadth of patients' feelings about their decision over time.

In addition, we learned that rather than focusing solely on quantitative measures, assessing regret could involve an opportunity for patients to share more about what they mean by quantitative ratings on scales. The responses in Table 1 reflect the confusion patients had but also highlight the fact that these unexpected responses, while valuable, are not currently quantifiable in the measurement tools. This qualitative exploration could allow the patient to elaborate on the process, options, and outcomes of their choice, forming a more complete description of the decision. For example, a patient might feel regret at the outcome of the decision (endorsing this quantitative statement on a validated decision regret scale: "The choice did me a lot of harm,") but, upon reflection, could also admit they would make that decision again, because it was their best option ("I would go for the same choice if I had to do it over again," another item on the same scale). These seemingly conflicting statements could benefit from qualitative elaboration so the patient could clarify whether they are experiencing outcome regret, yet feel little self-blame. This qualitative approach could also help account for the decision-making process as a variable in the analysis. Measured over time, the patient's regret could change, though, if they learn about alternative options, take more time to reflect on the reasons for their initial choice, or if a negative outcome progresses or improves. Giving a patient the opportunity to talk through their quantitative ratings can help them and researchers better understand how and why the patient responds to regret items on quantitative scales. If researchers and/or clinicians do not have the resources to ask these questions through interviews, adding open-ended survey responses could provide the opportunity for patients to elaborate on their quantitative responses.

Most importantly, as these standards for longitudinal assessment are developed, the questions used to measure regret should consider the impact that asking about regret might have on a patient. In our earlier example (Table 1), Patient 4_074 hadn't considered whether she regretted her choice of which breast cancer surgery to receive. When asked to rank her affinity with the statement "I regret the choice that was made," she was prompted to think about her experience in a way she hadn't previously. The patients who responded to the question without directly answering it, such as blaming others (Patient 4_181 in Table 1) or expressing disappointment at getting cancer (Patient 4_296), gave us a more complex view of their relationship with regret, in a way that the validated measure of decision regret used in the trial failed to assess. The question instead may have caused defensiveness or deflection. Regret is sometimes a difficult emotion to confront or accept. A measure that

accurately captures the complex view of regret must recognize the potential impact that questions about regret can have on study participants. Even if a measure does account for multiple types of regret and regret changes, asking a patient about process regret in particular can lead to emotional outcomes and an increase in regret from the process of reflection.

Because patients experience and respond to questions about regret in ways that exceed and elude academic definitions of the emotion, a mixed methods study (quantitative and qualitative) could explore with patients the best way to ask about regret and how to do so without prompting people to feel more regret as a result. Of the tools evaluated by Joseph-Williams and colleagues, none designed specifically for a healthcare context appear to have been developed using patient input. A patient-centric inquiry into the experience of the questions themselves could broaden the scope and process of measuring regret. Involving patient representatives from various diseases and conditions in the development of a tool could provide important insight into how questions may be experienced or interpreted, or the relative importance given to regret. The patient perspective can also help reveal to what extent the patient's relationship with their doctor (whether one of trust or doubt) impacts their willingness to admit or experience regret when questioned.

Further work also needs to be done to determine whether it's possible or desirable to have a single tool for any situation, as regret may be experienced differently depending on the type of decision being made. Our case example of the breast cancer decision-making study illuminates the limitations of existing measures for the specific type of decision those patients faced, but we must explore these experiences across a range of diseases and decision types to determine to what extent our observations are more broadly applicable. Future research might also explore latent needs, values, preferences, methods of obtaining information, and decision evaluation longitudinally.

3. Conclusion

Shared decision making can play an important role in minimizing regret, but, surprisingly, decision regret is rarely measured. In a systematic review of studies that measured the impact of decision aids on health-related decisions, Stacey and colleagues found that only 7 out of 105 studies measured the effect of the intervention on decision regret [21]. Six of those seven found no differences between intervention and comparison groups. All seven appeared to use the same validated regret scale [12] that was used in our breast cancer decision study. In the context of health-related decisions, more work is needed to capture experiences of regret over time and to understand responses to quantitative regret measures.

To fully understand the value of measuring decision regret as a meaningful outcome of shared decision making, we must establish a definition to clarify what we mean by regret. Next, we must consider ways of asking about regret in all of its complexity. Involving patients in the development of these measures, considering their input on self-reported quantitative measures in particular, can help us determine how best to bring up the subject of regret in a way that minimizes the emotional impact of the topic while accurately capturing its complexity. To draw full and accurate conclusions about a patient's values and

experiences, we must engage with patients at multiple points along their care journey, but more work should be done to consider the best appropriate time points. Could questions focused on measuring anticipated regret early on prevent the kind of retrospective regret experienced when asked about it later? And which methods for measuring temporal regret, including the best way to phrase measurement questions in quantitative surveys, should be used when interviews are not feasible? Moreover, including patients with different diagnoses who face various decisions can help determine whether it is possible to have one tool to measure decision regret, or whether multiple disease-based tools are needed to capture the differences in decision types. Decision regret can be a meaningful measure of the impact of shared decision making, but not until we can be sure we are accurately capturing it.

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Key Points for Decision Makers:

- Decision regret can be a useful indicator of the quality of healthcare decisions, but it is difficult to measure due to inconsistent definitions and the complex experiences of the emotion.
- To capture decision regret in a more meaningful way, clear and consistent definitions of the emotion and patient input are necessary to develop stronger measurement instruments.

Table 1.

Unexpected responses when asking about decision regret using validated measures [9, 12]

Patient experienced potential regret only upon reflection, when asked about it. Patient may not have experienced regret otherwise.	Patient 04_074 (three months post-surgery, unadjusted regret score = 20/100): In response to the item, "I regret the choice that was made," she responded, "I hadn't really thought about it that way. Knowing what I know now, I probably should have thought more about what questions to ask before the surgery."
Patient expressed frustration with others involved in the process, rather than reflecting on her own decision-making process	Patient 4_181 (one week post-surgery, unadjusted regret score = 50/100): In response to the item, "It was the right decision," she said, "It was the wrong decision for them not to tell me more. Why don't I have more details if you're going to take a chunk of my body out?"
Patient understood the question differently than intended	Patient 4_296 (one week post-surgery, unadjusted regret score = 45/100): Rather than reflecting on regret about the process of decision-making, patient expressed disappointment and sadness about getting cancer. In response to "the choice did me harm," she commented that of course the surgery hurt her body, but she didn't have a choice about whether to have surgery since she had breast cancer.
Patients had confusion about the questions in general	Several patients such as Patient 4_122 (one year post-surgery, unadjusted regret score = 0/100), Patient 4_351 (one week post-surgery, unadjusted regret score = 10/100), Patient 2_079 (one week post-surgery, unadjusted regret score = 5/100), Patient 2_096 (one week post-surgery, unadjusted regret score = 10/100) did not understand what was meant by the word "harm" for the decision regret item that states "This decision caused me harm." Patient 4_177 (one week post-surgery, unadjusted regret score = 10/100) had some inconsistent responses, and needed clarification from the interviewer to understand the first two items. Patient 4_077 (three months post-surgery, unadjusted regret score = 0/100) re-read the questions several times to understand how to respond.