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**Incorporating Patient Preferences into Cancer Care Decisions:
Challenges and Opportunities**

Running title: **Patient Preferences in Cancer Care**

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The need to incorporate patients' preferences into medical decision making has been highlighted as a key component of patient centered care (1). Furthermore, a high quality decision is one that is both informed and consistent with what the patient prefers and values (2). Yet, operationalizing these desirable outcomes by integrating patient preference elicitation into routine clinical care is difficult. In fact, research suggests that many patients do not feel that their preferences are assessed and that there is lack of concordance between what patients prefer and what their providers think they prefer (3-5). Moreover, the concept of "patients' preferences"

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is nebulous, and includes both treatment-specific and more global (e.g., quality of life, QoL) preferences. Addressing both in the context of treatment planning is daunting. With the increasing complexity of cancer care, ensuring patients can make high quality decisions, and especially that their preferences are considered, remains a challenge.

As reported in this issue of *Cancer*, Williams et al. (6) sought to evaluate how patients with cancer prioritize and communicate to clinicians their preferences and values around aspects of QoL (e.g., work, caregiving, financial toxicity), and whether and how oncology clinicians elicit and document such preferences. To do this, they evaluated both patient- and clinician-reported data. Patient clients of the non-profit cancer support organization CancerCare who were diagnosed with cancer in the past year were sent a one-time email containing a link to an 18-question online survey, and 320 completed it (33% response rate). Nearly all (95%) of the patient respondents were women, 59% with breast cancer, and 55% with early stage disease. While nearly two-thirds of patients reported that it is very or extremely important to them that their doctor knows their personal priorities regarding their family, work, hobbies, key events, and household and caregiving duties, and 63% reported that they had ever discussed what is important to them personally with their main cancer doctor, only 37% reported that they had discussed what was important to them with their doctor *before* starting cancer treatment. Consistent with work by others (7-8), Williams et al also found variation in patients' priorities, particularly by age and disease stage. While the study sample was limited by the small number of male respondents and lack of information regarding patients' race, ethnicity, and socioeconomic status, it is likely that patients' priorities also vary by these factors. This individual nature of patient preferences contributes to the challenge clinicians face in assessing and incorporating them into clinical care.

In the Williams et al. study, oncology clinicians (hematologists, oncologists, other physicians who care for patients with cancer, and oncology advanced practitioners) were recruited to the study via a market research panel and were sent a one-time email containing a link to a 22-question online survey. A total of 112 completed it (5% response rate); most were hematologists/oncologists, more than half reported practicing in a community setting, and most reported spending more than two-thirds of their of their time in direct patient care. About two-thirds (67%) of clinicians reported that they know patients' preferences and priorities before their treatment plan is finalized; 68% reported that this information has a large or major impact on treatment recommendations, and 63% reported that this information is documented in the medical record. It is unclear if this approximate two-thirds of the clinician sample represents essentially the same group answering "yes" to these questions, meaning that about a third of

clinicians do not typically know preferences prior to treatment planning, feel preferences have a large impact on treatment planning, or have preferences documented in the medical chart.

These findings support the lack of concordance between patient and clinician perceptions of preference discussions, with only about a third of patients reporting their preferences were discussed before starting treatment and two-thirds of clinicians indicating they know these priorities in advance. The authors' findings are also suggestive of a troubling gap between what patients *want* their clinicians to know about their personal preferences and priorities and what clinicians *actually* know and document. Nearly all patients reported that mental function (98%), living independently (97%), and being able to pay for treatment without major financial hardship (96%) are very/extremely important to them as a person living with cancer. Yet the issues that were most reported by patients as having been discussed with their clinical team before treatment were the ability to work (73%), availability of care partners for help and support (71%), and transportation and travel time to treatment (69%). These results add to those of others that have found a lack of alignment between patients and clinicians (3-5) and underscore the need to better understand where communication gaps lie.

Some important methodologic issues must be considered in interpreting these results. First, it is important to note that these were not paired surveys—the clinician respondents were not necessarily the treating clinicians for the patient respondents—making it more difficult to draw conclusions around patient-clinician concordance. Moreover, the low response rates of both samples make them subject to bias. It is very possible that the responding clinicians (5% of those invited) are those who are also most likely to engage in priority setting with their own patients in advance of treatment planning. Similarly, the 33% of patients who responded may be those most unhappy with the care process (including a lack of preference assessment) they experienced. While the Williams et al. finding that patients' key preferences may not be discussed prior to treatment is potentially concerning, it is also possible that the lack of concordance found in this study may be at least partially attributable to the framing of the survey questions. The survey question asking patients about the importance of priorities asks them how important these are “as a person living with cancer.” It is conceivable, and even likely, that patients' priorities shift throughout the cancer care continuum, and that patients' priorities before they obtain treatment are different than their priorities as a person living with cancer during and after treatment. Moreover, patients did indicate that some preferences that may be more germane to treatment decision-making—ability to work, have care support, and transportation—were assessed before treatment. This again points to the difficult task for clinicians of assessing *both* treatment-specific and QoL-specific preferences in the context of treatment planning.

Yet the Williams et al. study underscores how important QoL-related issues are to patients, and how such preferences may need to be considered earlier in the cancer care trajectory. In particular, a striking finding pertains to financial toxicity, a growing area of concern in cancer care. The authors found that 95% of patient respondents reported that out-of-pocket expenses are very/extremely important to them as a person living with cancer, but only 59% reported discussing this issue with their cancer care team before the treatment plan was finalized. Even if some patients do not prioritize out-of-pocket expenses as highly before treatment as they do during or after treatment, this finding of an apparent gap is supported by a large and growing body of literature about the patient-level financial consequences of cancer treatment. For example, Jagsi et al. (9) surveyed 2,502 women with early stage breast cancer reported to the Georgia and Los Angeles County SEER registries (68% response rate) and 845 of their treating clinicians (surgeons, medical oncologists, and radiation oncologists; 60% response rate) regarding clinical discussions of financial toxicity. Similar to Williams et al., Jagsi and colleagues (9) identified differences in perceptions of discussions about this issue; while many clinicians reported discussing costs and financial burden with patients, patients still reported high unmet needs for engagement with clinicians regarding their financial concerns. A study by Warsame et al. (10) used different methodology and analyzed 529 audio recordings of clinical encounters in three different oncology clinics, and found similar patient-clinician discordance. Discussions of financial issues occurred in only 28% of recordings, were almost always initiated by the patient or their caregiver, and only 60% of cost concerns raised by patients or caregivers were verbally acknowledged by the clinician. Collectively, these studies and that by Williams et al. support an urgent need to develop and implement strategies to help oncology clinicians elicit and address patients' financial priorities at the time of treatment planning and beyond.

A strength of the study by Williams et al. is the inclusion of clinicians' perceptions about the *process* of eliciting patients' priorities. Despite recommendations that patient preferences should be incorporated into clinical decision making, few recommending bodies offer suggestions about how this should be done, and little is known about how clinicians themselves feel about doing this. Interestingly, Williams et al. found that over half of the clinician respondents reported thinking that it would be infeasible to collect and document patients' preferences and priorities prior to finalizing treatment plans. However, when asked about specific methods to collect patient preferences, 52% of the respondents (out of an N of 89 due to some clinicians not answering this set of questions) reported that it would be easy or extremely easy to use paper or tablet forms to collect such information from patients prior to

their first appointment. Conversely, 51% of clinicians reported that it would be difficult or impossible to collect such information via a phone conversation between office staff and patients prior to their first appointment. These findings suggest that clinicians may be more open to methods for engaging patients in priority setting ahead of, rather than during, clinical encounters.

Given the complexity and time-limited nature of most clinical encounters, such findings further support the critical need for tools that can inform and allow patients to generate a priority list outside the visit and come prepared with their own preferences clarified for discussion. Such tools could allow for the assessment of both treatment-specific and QoL-related preferences. In fact, this is the intent of patient decision aids—which are predicated on informing and clarifying patient values. While cancer focused decision aids have been shown to positively impact patient knowledge and promote values clarification (11), few have been integrated into clinical workflow to promote shared decision making (12). Though difficult, integrating tools and aids into the electronic health record is feasible (13) and sorely needed to foster shared decision making, while taking the onus off the clinician to elicit and document patient preferences. Or, as suggested by the Williams et al. study, a first step may be provision of tablets in the clinical setting to allow for preference assessment ahead of the visit.

Another untapped method for promoting the incorporation of patients' preferences into treatment planning is the engagement of key decision supporters (e.g., spouses/partners, adult children, family and friends). In prior work, we found that decision supporters' engagement in treatment decision making was associated with improved patient decision appraisal (14). Engaging and involving these key others – who typically attend visits, take notes and make decisions with patients—offers an opportunity to help ensure that patients' preferences are conveyed to their clinicians. By priming and including them in clinical discussions, decision supporters may be able to advocate for preferences that are difficult for the patient to convey.

Observational survey work, such as that presented by Williams and colleagues, remains a cornerstone of health services research. As such, it must achieve the highest standards to be most impactful. A key issue raised by the authors, and noted above, relates to the low response rates for both patients and clinicians. Not only does this translate to often biased responses, it also makes large-scale generalizability and reproducibility more difficult. Work by our team collaborating with population-based cancer registries using the rigorous Dillman method (15) has resulted in response rates from patients of 70%, and 60-70% for clinicians (9, 16), as has work by others (17). Survey research is often the important first step in the scientific assessment of a problem with cancer care delivery that is then used as a basis for intervention development.

As a result, ensuring that the data on which future steps are based is representative and generalizable is critical.

The 2001 IOM report “Crossing the Quality Chasm” first defined patient-centered care, as care that is responsive to “...patients’ values and preferences, needs and values, and ensures patient values guide all clinical decisions” (1). Since then, there has been ongoing recognition of the need to ensure that what matters most to patients—their preferences, values and personal priorities—is part of clinical decision making. Challenges to achieving this goal have been identified, including lack of time, lack of training of clinicians to do preference elicitation, and general lack of concordance between what patients value and what their clinicians think they value. Despite the methodologic limitations described above, the study by Williams et al. has confirmed a gap between patients and clinicians around what preferences and values matter most, and thus implies a continued gap in delivery of patient-centered cancer care. Nearly 20 years after the IOM report, such findings suggest that clinicians need assistance to ensure that patients’ preferences—both treatment-specific and broader QoL preferences—are incorporated into treatment planning.

Opportunities to improve patient-centered care exist, and should be further developed. The most needed approaches are those that leverage technology through the integration of decision support tools into the clinical workflow, to promote patient preference assessment and provide reports and feedback to clinicians for use in treatment planning. Interventions that involve key decision support persons can also offer a unique opportunity to close communication gaps between patients and clinicians. Without such innovations, ensuring that patients’ preferences are fully incorporated into cancer care planning will remain a challenge. It is time to move beyond documenting discrepancies in patient-clinician preference setting to ensuring patients’ preferences and values are routinely included in treatment planning.

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