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Assessment of Individual Patient Preferences to Inform Clinical Practice

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CONFLICTS OF INTEREST

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Health preference research (HPR) enumerates the tradeoffs that patients are willing to make between different healthcare attributes and the value that they place on competing alternatives [1]. Most preference studies consider “mean” preference estimates across populations in order to inform resource allocation decisions. However, clinical care is directed toward the individual patient. Therefore, individual-level preferences are required in order to inform decision making and to help patients choose between alternative treatments and services. Patients who know and understand their preferences may experience less decisional regret, increased levels of satisfaction, and improved communication with their healthcare providers [2].

HPR use preference elicitation methods such as the *discrete choice experiment* (DCE) to elicit individual patient preferences. Such studies are becoming more frequent, particularly in settings characterized by patient-centered rather than access-driven approaches to healthcare provision. Nevertheless, they are still limited. While the methods for identifying and communicating individual preferences are less advanced than those for population preferences, innovative approaches have the potential to rapidly develop the elicitation of individual preferences.

In this era of greater personalization of medicine, it is time for stakeholders to consider the rationale for evaluating individual patient preferences and reach consensus on when and how to ascertain them in order to inform *shared decision making* (SDM). This paper reviews the measurement of individual patient preferences, examines how we can translate them into individual treatment plans, and investigates how they can be adopted in a way that enhances change in the healthcare system. We highlight some aspects in which the field is moving forward, but also allude to knowledge gaps in which research is needed to support the benefits of using individual patient preferences to inform healthcare decisions and to discover the optimal approaches for measuring them and incorporating them into clinical practice.

Why Conduct a Formal Assessment of Individual Patient Preferences?

SDM is an interactive process involving the input of both a clinician and a patient who work together to make a choice between competing healthcare alternatives. Meta-analyses have shown that SDM can result in improved patient knowledge, decreased decisional conflict and greater patient satisfaction with their care [2]. Additionally, SDM can reduce the rate of invasive procedures and have a positive impact on health inequalities [3]. In the United States (U.S.), policymakers have acknowledged the potential of SDM to improve value in care by specifically highlighting its role in the Affordable Care Act. While SDM can be implemented across various levels of patient participation, it is always informed by an individual patient’s values, priorities, or preferences.

Explicitly incorporating patient preferences into SDM is particularly important when there are competing alternatives with important harm-benefit tradeoffs, high levels of uncertainty in treatment outcomes, or when choices are likely to differ across patients based on individual values. While physicians may believe that they are able to assess their patients’ preferences for care during routine clinical encounters, physicians’ perceptions may differ substantially from patients’ actual preferences. This gap is clinically relevant because optimizing patient care frequently hinges on accurate preference identification. Notable examples of preference-sensitive decisions include the treatment for early stage breast and prostate cancer, lung cancer screening, the prevention of initial variceal haemorrhage, and some elective orthopaedic surgeries (for further discussion of preference-sensitive care see the Dartmouth Atlas of Health Care topic briefs available online [4]). SDM may be less feasible in high-acuity settings, but **could** be of particular use in relation to chronic conditions where patient engagement is imperative.

Despite the accepted benefits of SDM and the ethical imperative to incorporate individual patient preferences into treatment plans, the empirical evidence that supports how to measure individual patient preferences is limited. Relatively few studies have investigated using preference instruments in clinical practice. A recent review showed that 40% (n=134) of studies that utilized such methods were developed to be used in clinical decisions [5]. However, few have actually been tested in a healthcare setting. Below, we consider several topics that contribute to this gap in knowledge.

Challenges in Individual Preference Assessment

In principle, it is possible to obtain individual preferences for competing alternatives using DCEs [1, 6]. However, the capacity of a given statistical model to accurately measure preferences using the DCE responses from a single respondent has not been definitively established. Estimates of “mean” patient preferences can be generated based on relatively few respondents each answering a small number of choice tasks. In contrast, a larger number of choice tasks are needed in order to provide sufficient responses to obtain accurate preferences from a single respondent. Some studies have demonstrated the merits of alternative approaches like *best-worst scaling* in estimating patient preferences at the individual patient level [6-8]; and have also shown that including such preference assessment can result in improvements in decisional quality beyond what is achieved in educational decision aids in the setting of SDM .

Regardless of the method used, the choice of which attributes and levels to include in a preference survey poses a significant challenge. Preference assessment requires that individual patients be given the opportunity to consider the attributes and levels that are necessary for them to choose between competing alternatives. However, these criteria are likely to differ between patients. Both the omission of critical attributes and the inclusion of irrelevant attributes will significantly impact the preference estimates of individual patients.

Unlike health valuation surveys, SDM needs to describe complete and sometimes lengthy lists of treatment attributes in order to fully designate a clinical decision. The cognitive burden of this task can be problematic for some respondents. For example, when describing the “benefits” of a treatment, important attributes not only include the specific outcomes related to the benefits, but the percentage of patients responding as well as the magnitude of the response. The inclusion of multiple benefits (such as pain relief and improvement in function) also makes it challenging to ensure that attributes are independent from each other, a requirement for most preference-elicitation methods. A concern beyond ensuring an appropriate set of attributes and levels, moreover, is the increasing recognition of the importance of non-treatment attributes such as emotion, context, and the opinions of others, which may factor into an individual patient's decision. Further research is needed in order to examine how best to incorporate these factors into preference-elicitation tasks.

Integrating the Routine Use of Individual Preference Assessment into Clinical Practice

The barriers to integrating patients' preferences into treatment planning extend beyond the construction of preference surveys. Studies have shown that treatment plans frequently do not match patient preferences even after decision aids are used [2]. For SDM to occur, physicians must recognize the decisions as preference-sensitive, engage their patients in discussions about the pros and cons of the available alternatives, clarify which alternative fits best with each patient's preferences, and be comfortable following their patients' desired paths even when they are not concordant with the physician's own preferences. The added time that is required to adhere to these steps is the most frequently cited barrier to their adoption. Implementation studies that examine how to cue patients and physicians about which decisions are most likely to benefit from an SDM process, on how and when to use decision aids, and how to involve

other members of the treatment team are imperative to advancing the field from one that produces and evaluates decision aids to one that actualizes SDM in clinical practice.

An additional gap in the literature is how to incorporate SDM into a changing healthcare system in which physicians are incentivized to adhere to clinical practice guidelines and to achieve specific quality metrics. For example, physicians working in one of the Centers for Medicare and Medicaid Services' Accountable Care Organization models are exposed to some degree of shared risk for a population, although they cannot compel Medicare beneficiaries to seek treatment within their system for care. Expensive care received outside of a system is still attributed to the system. Previous efforts to "manage care" in the U.S. were met with resistance on the part of physicians and patients in part because guidelines cannot be personalized to individual needs; the phrase "cookbook medicine" arose as a pejorative description of such care.

However, guidelines that allow for variation based on specific measured and documented patient preferences can meet the needs of patients to be heard and cared for as individuals. Patients who feel "heard" and engaged in their own care, furthermore, may be more likely to stay with the provider that gives them the tools to express themselves. Such an approach can help health systems to succeed in a paradigm in which they are rewarded for high-value care from a utilization perspective. Indeed, some large healthcare systems in the U.S. (UCLA, Johns Hopkins, UNC Chapel Hill, Providence) are already experimenting with the routine use of preference assessment in the clinic visit, and some have reported improvements in decisional quality and patient satisfaction [9]. Perhaps changes in the global healthcare system will provide the impetus for researchers, physicians, and policymakers to close the gaps in our knowledge of how best to characterize and utilize individual preferences for healthcare.

Next Steps in Individual Preference Assessment

Clearly, a robust research agenda is needed in order to optimize the methodologies for measuring individual preferences and identify how to most effectively implement these preferences into routine care. However, the imperative to increase healthcare value that has dominated policy in the U.S. and other nations has already set the stage for the routine use of preference assessment in patients as they make important medical decisions with their physicians. In the emerging era of "precision medicine", the use of generic clinical guidelines to guide individual care has been challenged by both patients and physicians. As described earlier, decades of research have shown that healthcare value is maximized when patients are fully informed and encouraged to make choices that are in alignment with their individual preferences.

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