Information Quality Challenges in Shared Healthcare Decision Making

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Healthcare is evolving towards patient-centered care. Of particular interest is Shared Healthcare Decision Making (SHDM) defined here as a collaborative process of patients and physicians making healthcare decisions together, taking into account the best scientific evidence available, as well as the patients' knowledge and preferences (Oshima Lee and Emanuel 2013). Compared to traditional decision-making based on authoritarian role of physicians, SHDM tends to be more sensitive to complex trade-offs of healthcare. Indeed, few healthcare decisions involve a clear optimal choice. For example, a man diagnosed with localized prostate cancer faces several choices. Surgery produces better urine flow at the risk of incontinence and impotence. Radiation therapy is nonsurgical, but it can cause long-term side effects and is also more expensive. Watchful waiting, while less expensive, can be catastrophic if cancer progresses rapidly. Relaying the clinical consequences of different options is traditionally in the hands of doctors, who generally steer people toward more aggressive treatments (Cutler 2014). With access to appropriate information about the trade-offs, it is believed, patients can take a more active role in their own care (Oshima Lee and Emanuel 2013).

Information quality (IQ) is key to empowering patients to make informed decisions. The Internet and social media give patients access to more information, including information from patients themselves (Kallinikos and Tempini 2014; Lukyanenko and Parsons 2015). However, the progress

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on SHDM is impeded by the many unresolved IQ challenges arising in this novel domain. To illustrate, we focus on a few prominent ones:

- *Obtaining, Preparing and Evaluating Information.* With the explosion of online care-related information, current research considers issues of accuracy and reliability of the information (e.g., Gao et al. (2015)). However, as patients engage in SHDM, another important concern is the ability for patients to assimilate, reconcile, and integrate data coming from a variety of sources. An advantage of the emerging online content is its broad coverage beyond strictly medical facts (Kallinikos and Tempini 2014)—making it particularly valuable for complex trade-offs of SHDM (Chen 2015). Yet, it is clearly a challenge for patients to gather all necessary information and make sense of it in order to understand the big picture. Moreover, the different information about care quality may be based more on opinions than actual randomized data, and thus likely to suffer from the classical selection bias (Gao et al. 2015). For example, De Choudhury et al. (2014) found notable differences in perceptions of information quality by patients seeking health information on the Internet. A challenge therefore is to reconcile disperse and often contradictory sources and then provide patient-specific means of ascertaining IQ.
- *Integrating Interactive Decision Aids.* Interactive decision aids (IDA) (Häubl and Trifts 2000), such as recommendation agents or comparison matrices, convey information to patients about benefits and risks of various treatment options and have been shown to improve "evidence-based decision-making" (Stacey et al. 2011). Within the context of the physician-patient relationship, IDA also provide additional information for patients to utilize while evaluating different choices after a given physician's recommendation. Yet, the assumptions and normative heuristics embedded in the aids may possibly be at odds with each patient's values, experiences, and beliefs (Williams and Calnan 1996; Charles et al. 1999). A key challenge, therefore, lies in effective integration of IDA into the complex and non-linear process of care, including alignment of aids' guidance with the views of the patient.

We believe the solutions to the SHDM challenges require both theoretical and technological advances. To help patients make sense of the explosive volume of disparate sources, an important technological solution is the creation of a patient-facing system capable of finding relevant information, parsing, and integrating a variety of sources and interpreting the results to the patients via a user-friendly IDA. Here one challenge is finding all relevant information, which can be supported by work on automatic knowledge discovery and integration (e.g., Endicott et al. (2017) and Larsen and Bong (2016)) and identification and reconciliation of information gaps and biases (e.g., Tremblay et al. (2010)). Current search and ranking methods have room for improvement in helping users get more accurate and useful information (Wang et al. 2012). Credibility-specific analogues, such as Twitter's "verified account" seal can be developed for health websites, that contain verification of content accuracy (De Choudhury et al. 2014). Another challenge is translating between scientific and layperson vocabulary, which can be accomplished by building integrative domain ontologies and natural language processing (e.g., by extending the pioneering work of the systems like IBM Watson (Davison and Forbes 2015)). Moreover, the integrative system should remain sensitive to the variable and highly personal needs and values of patients—motivating future work on value modeling (to translate human values into machine language) and value-based designs (to action human values appropriately and transparently to the users) (Aksoy et al. 2006). Finally, work is needed on increasing the effectiveness of IDA's visualization, including ability to present complex trade-offs, allowing users to manipulate decision weights to reflect individual conceptual and value models.

To be effective, the technological solutions outlined earlier should be coupled with corresponding advances in IQ theory. One theoretical solution lies in moving beyond popular IQ dimensions (e.g., accuracy), and expanding our understanding of believability, objectivity, reputation, consistency, interpretability, and accessibility, to better support patients facing inherently uncertain, disperse, and inconsistent information sources. Further, the holistic nature of decision making in SHDM may benefit from rethinking the traditional theorization of IQ (as comprised of underlying dimensions) and begin to conceptualize IQ as a holistic, big-picture construct.

In summary, healthcare data and the holistic nature of healthcare decision-making present unique challenges and opportunities for IQ researchers. More research efforts and novel solutions in both IQ theory and applications are needed to support the on-going transion of healthcare to SHDM.

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