

**2017 ASIS&T SIG-USE Symposium:
Framing Inclusion and Exclusion in Information Behavior Research and Practice**

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Health Justice: The Central Roles of Health Literacy and Information Behavior

Health justice – the idea that every individual is morally entitled to “a sufficient and equitable capability to be healthy” (Venkatapuram, 2011, p. 20) – will be unattainable as long as groups of people and/or individuals encounter information behavior-related barriers. Although information has certainly become more ubiquitous and accessible for many people, for some it has not. Access to health information, in particular, remains elusive for many people, particularly those who are elderly, have a low income (< \$25,000), have not completed high school, lack health insurance, and/or are from outside the U.S. (Kelley, Su, & Britigan, 2016). Furthermore, increased volumes of information and improved convenience of access do not automatically translate into people having more of the information that will be relevant, understandable, credible, usable, actionable, and useful for them. Health justice will remain out of reach for people who have limited health literacy, which has been defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health care decisions” (Ratzan & Parker, 2000). Unfortunately, nearly 90% of U.S. adults have a below-proficient level of health literacy (Kutner et al., 2006) and low levels of health literacy are particularly prevalent among disadvantaged (i.e., older, low-income, minority, and immigrant) populations (NN/LM, 2014). Health literacy levels are important, as they have been found to be correlated with a lower likelihood of obtaining preventative healthcare services (Bennett et al., 2009, IOM, 2004); a greater likelihood of not receiving a diagnosis of a serious disease, such as cancer, until much later in the course of the disease (Merriman, Ades, & Seffrin, 2002); and a higher probability of ending up hospitalized and experiencing poor health outcomes (Ad Hoc Committee on Health Literacy, 1999; Baker et al., 2002 & 2007; IOM, 2004; Schillinger et al., 2002). Low health literacy also plays a central role in the development and persistence of health disparities. In fact, an individual’s health literacy has been found to be a stronger predictor of their health than their age, race, educational level, employment status, and income (Weiss, 2007).

Many models and theories of information behavior assume a neat progression from information need to information seeking to information use; however, in actuality, at each of these steps, as well as before and following them, there is the potential for exclusion. The field of information behavior originated largely in studies of library usage, which focused much more on the holdings of the library rather than on the users themselves, the nature of their actual information needs, and the purposes for which they sought information. In most cases, it could be safely assumed that the user had arrived at the library with an information need in mind, although they may have had only a visceral (Taylor, 1968) sense they were missing information or a vague awareness they had an anomalous state of knowledge (ASK) (Belkin, 1980; Belkin, Oddy, & Brooks, 1982). It also could be fairly safely assumed that they were at the library to look for this

information and that they had hopes/plans of putting this information to use. Outside of the library setting and particularly in cases of everyday life information seeking, however, information needs and information behavior, more broadly, are infrequently this neat. Although they are far less frequently studied than information seeking processes, information needs are integral to information behavior. Without an awareness of an information need, purposive information seeking may not unfold and more passive forms of information seeking may not be successful as the person may be unable to recognize the relevance and potential usefulness of any information that happens to cross their path. Unfortunately, disadvantaged people are likely at a higher risk for this, particularly due to their tendency to have lower health literacy levels and reduced access to information resources. Lower levels of health-related motivation and self-efficacy, along with a heightened sense of fatalism in regard to their health, may further exacerbate this situation.

Drawing on a large ($n = 3,677$), nationally- representative survey data set (the U.S. National Cancer Institute's 2014 Health Information National Trends Survey (HINTS)), we investigated the prevalence of information avoidance (i.e., agreement that "I'd rather not know my chance of getting cancer") among the U.S. adult population and identifies associations between information avoidance and other types of demographic, information-seeking, cognitive/perceptual, and social factors (see St. Jean et al., 2017). Our goal was to explore whether and how the concepts of information avoidance, health literacy, and health justice are interrelated. Our findings confirmed these interrelationships and revealed that information avoidance is not uncommon (31% strongly or somewhat agreed that they would rather not know their chance of getting cancer) among U.S. adults; however, it is significantly more common among the very people who tend to be negatively impacted by the lack of health justice in this country and who tend to have low levels of health literacy: older people (NN/LM, 2014), people with lower household incomes (Chetty et al., 2016; NN/LM, 2014), and people with lower educational attainment levels (Olshansky et al., 2012). Information avoidance was also found to correlate with being unemployed, disabled, or retired; lacking healthcare coverage; not using the Internet; encountering difficulties in searching for cancer information; placing less trust in some sources of cancer information (including doctors, government health agencies, and the Internet); lower health-related self-efficacy; higher perceived cancer incidence but lower perceived susceptibility to cancer; less perceived social support; and a preference for a less collaborative role in cancer treatment- related decision-making.

Many of these related variables pose possible avenues through which we might interrupt the connections between low health literacy, poor health outcomes, and, ultimately, health disparities (as established in, for example, IOM, 2004, Schillinger et al., 2002, Weiss, 2007). While demographic variables are often impossible (or quite difficult) to change, we can work to ensure that everyone has healthcare coverage, Internet access, and the health and information literacy skills needed to reduce the barriers they may encounter when seeking health information. Furthermore, we can help to increase people's health-related self-efficacy and provide them with an accurate picture of both the incidence of cancer and their personal susceptibility. We can also make strides toward ensuring that people have the social support they need and a particular health professional in whom they can place their trust and whom they are able to see and rely upon when they need healthcare. We can also educate people about the potential benefits of taking a more collaborative role in treatment- related decision-making, enabling them to benefit

from their doctor's expertise and experience while also being able to make an informed decision about the treatment option that they believe will be the best for them.

For every individual to have equitable opportunities to live a long and healthy life, information is key, although insufficient in and of itself. One cannot improve their health trajectory or increase their chances of reaching a positive health outcome simply by having information. Information is meaningless if its possessor cannot understand it, perceive its relevance to their own situation, and/or adapt (if needed) and act on it. Ideally, a person's information behaviors facilitate their development of an awareness of their information needs and of the ability to specify and articulate these in a timely fashion; enable them to obtain accurate, personally relevant, actionable information; and support their development of the motivation and self-efficacy needed to act on this information. However, this ideal situation rests heavily upon an individual having adequate health literacy, awareness of and access to credible sources of health information, and access to the numerous resources necessary to be able to act on information, such as health insurance, money, and time.

Information behaviors can serve to exclude and further disadvantage the already-disadvantaged; however, we, as information professionals and as information behavior researchers, can take action to interrupt this progression, working toward reducing health disparities and improving the state of health justice in this country. Information professionals and information behavior researchers can reach out to underserved populations, offering programs, services, and resources that can improve their health literacy levels, their information seeking skills, and their motivation and self-efficacy to find and act on information to positively influence their health trajectories. Additionally, addressing the structural and institutional barriers that frequently affect individuals with limited health literacy will be critical. Allocating sufficient resources for these individuals through alterations in clinical workforce compositions, clinical workflows, and current processes of care can help to counteract demographic disadvantages and optimize the quality and efficacy of the healthcare they receive. Educational strategies in parallel with organizational changes can enable us to make tremendous progress toward reducing health disparities.

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