

On the Centrality of Information Appraisal in Health Literacy Research

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This article aims to make the case for the centrality of, and the lack of attention to, health information appraisal in health literacy research. First, it will be shown that how citizens and patients interact with health information has changed dramatically in the last decades, after the shift toward patient-centered health care and the increase in publicly available health information. Second, it will be argued that although these changes have had a profound effect on how people's interactions with health information should be studied, research has not been able to fully reflect the changes. More specifically, after presenting an example making the case for the centrality of health information appraisal, it will be shown how health literacy research still has a strong focus on its functional component. The main implications of the lack of attention to the dimension of health information appraisal will be discussed and possible future directions to advance health literacy research will be suggested.

FROM NO INFORMATION TO TOO MUCH INFORMATION

Two major societal changes occurred recently that have had a profound impact in shaping the way we interact with health information. The first is the transition from a pater-

nalistic doctor-centered approach to medical care to a more patient-centered one (Charles, Gafni, & Whelan, 1997). The former was characterized by a strong asymmetry of knowledge and power in favor of the physician, who was responsible for making all health-related decisions on behalf of the patient. In the patient-centered approach, patients have the right and are expected to have a say in their medical care (Barry & Edgman-Levitan, 2012). Research has shown that patients who are involved in medical decisions present a series of improved health outcomes, such as increased adherence to treatments or higher satisfaction (Joosten et al., 2008). For this to happen, however, it is crucial for patients to have all the relevant information needed to make an informed decision.

The second societal change that has contributed to making it possible to have this information was the advent of the Internet, which has revolutionized the landscape of health information (Viswanath, 2004). Historically, medical knowledge has been the exclusive domain of a restricted group comprised of health care professionals and scientists. After the digitalization of information and the possibility offered by modern technologies to make all of this information available across the globe, this is no longer true. Now, people are

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potentially able to access all kinds of medical information from the comfort of their home with the click of a mouse or on their smartphone. Even more importantly, everyone can now easily produce health information and make it available to others, regardless of his or her qualifications (Amann, Rubinelli, & Kreps, 2015). Thus, many citizens and patients now often find themselves in the situation of being overwhelmed by health information when they are required to make an informed decision regarding their medical care. In some cases, they are even at risk of making a decision that will have a negative impact on their health (Cline & Haynes, 2001).

A CASE IN POINT: ANGELINA JOLIE'S "MY MEDICAL CHOICE"

In 2013, American actress Angelina Jolie announced through a column in *The New York Times*, entitled "My medical choice," that she had decided to undergo a bilateral risk-reducing mastectomy after the discovery that she carried a rare *BRCA1* gene mutation, putting her at an 87% lifetime risk of breast cancer. She also explained how, after the mastectomy, her lifetime risk of developing breast cancer was reduced to less than 5%, a risk well below that of the general female population. The announcement received an unprecedented amount of public attention, with Jolie's choice being discussed on news media and social media worldwide. The announcement stimulated the debate about genetic testing (and online searches for cancer genetics skyrocketed), but it also had a measurable effect on health-related behaviors and outcomes, such as increases in primary care providers' referrals to genetic counseling, genetic testing, and even in demands for risk-reducing surgery (Noar, Althouse, Ayers, Francis, & Ribisl, 2015; Roberts & Dusetzina, 2017).

Arguably, for those women who were at a high risk of carrying the genetic mutation but who were not aware of it, Jolie's decision to go public about her choice can be considered a great public service, as it contributed to raising public awareness of the issue (Borzekowski, Guan, Smith, Erby, & Roter, 2014). If we consider the population prevalence of the genetic mutation, however, it is also easy to see how this revelation had some undesirable consequences. For 99.7% of women in the population—those at low risk—Jolie's announcement might have caused unnecessary worries and anxiety, conflicts with health care providers, and unnecessary testing and surgeries (Roberts & Dusetzina, 2017).

Leaving aside ethical considerations (which are outside the scope of this piece), this example clearly illustrates how health information can have an impact on medical decision-making and, in turn, on health-related and societal outcomes. Whether these outcomes are good or bad depends on

several factors, among which a fundamental role is played by a person's ability to comprehend and deal with health information.

HEALTH LITERACY RESEARCH: ACCOMPLISHMENTS AND OPEN CHALLENGES

People's ability to deal with health information has been the main topic of investigation of health literacy research (Nutbeam, 2008). Over the years, the concept has evolved from merely referring to a set of technical skills applied to the health context to a reflection of the changing landscape of health information; now, health literacy encompasses more advanced skills across different domains, such as accessing, understanding, appraising, and applying information relevant to health (Sørensen et al., 2012). Among the different domains, health information appraisal is becoming increasingly central. Jolie's case illustrates this clearly. First, women could access information easily; in fact, they did not even have to search, as this information was broadcast to them through various types of media. Considering the "Angelina effect" described above, it can also be concluded that women could understand her message and apply the new information for their health-related decisions. Yet, all those women who were not at risk but who nevertheless decided to act on the information clearly lacked information appraisal skills, such as the ability to understand that the information might not be relevant to them or that a single woman's experience might not be generalizable to all women.

The centrality of health information appraisal for health literacy, and therefore for the overall population's health, is well recognized by the academic community and by leading world health authorities. At the same time, however, most empirical research about health literacy still focuses on other domains, in particular on functional health literacy, which refers to one's ability to locate, read, and understand health information (Aldoory, 2017). The instruments that are routinely used in health literacy research show this clearly. Whereas most of them assess functional health literacy skills, only a few measure information appraisal (Pleasant, McKinney, & Rikard, 2011). The latter, moreover, are usually designed to measure health literacy as a broader construct (i.e., covering all its domains) and include only a few items to assess health information appraisal. One example is the section of the Health Literacy Questionnaire dedicated to health information appraisal. It includes five items covering one's ability to distinguish between good and bad information and to resolve contradictory information, whereas other potentially relevant aspects (such as the ability to assess the relevance of information) are left unexplored (Osborne, Batterham, Elsworth, Hawkins, & Buchbinder, 2013). These

tools can certainly provide researchers with insights on the information appraisal skills of people, yet they are not sufficiently detailed to fully capture the complexity of this aspect.

As pointed out earlier, the lack of dedicated measures of health information appraisal (and of studies investigating this aspect) should not be ascribed to a lack of interest in the issue. Rather, it traces back to the lack of a clear definition and operationalization of this health literacy domain. So far, only a few endeavors have been conducted to clarify the “critical dimension” of health literacy, and they have remained at a theoretical level, not providing a usable operational definition of health information appraisal (Chinn, 2011). Thus, although there is consensus on the fact that the ability to appraise health information is a fundamental set of skills to master in today’s world, we do not know what these skills are.

IMPLICATIONS AND FUTURE DIRECTIONS

Enhancing health literacy skills at the population level is considered a promising approach to preventing chronic disease, disability, and early death, as well as to lowering overall health care costs (Pleasant, Cabe, Patel, Cosenza, & Carmona, 2015). The implications of an incomplete theorization, operationalization, and measurement of the domain of health information appraisal are manifold. First, this conceptual and empirical gap limits the exploration of the pathways linking health literacy and health outcomes, which have thus far been explored almost entirely just for functional health literacy (Berkman et al., 2011). Second, the lack of a specific measure might leave important literacy gaps undetected (Haun, Valerio, McCormack, Sørensen, & Paasche-Orlow, 2014). For instance, someone with high functional health literacy skills could lack the ability to appraise health information. Above all, without a clearer understanding and a systematic measurement of health information appraisal, it is impossible to design and evaluate interventions aimed at addressing people’s critical health literacy skills (Barry, D’Eath, & Sixsmith, 2013).

Traditional health literacy studies focusing on functional health literacy and aiming at providing people with basic literacy skills and making health information accessible to everybody are extremely important and have helped to improve access to health care by the more vulnerable members of the population. However, especially in affluent countries, health literacy problems will more and more look like the example of Angelina Jolie discussed above. This makes it clear that health information appraisal skills could be considered the basic skills of the health care consumer of the future. Only by understanding what these skills are, how to assess them, and most importantly, how to transfer them to the population

will it be possible to reach the goal of citizen and patient participation and autonomy as called for by the patient-centered approach.

Undeniably, major efforts are still needed at the system level. This means finding ways to make the health care system easier to navigate, to ensure that everyone has easy access to understandable health information, and to put in place system improvements to make health information easier to appraise, such as by encouraging health information providers to adhere to established quality guidelines. However, future research should also focus on making the dimension of health information appraisal more prominent in the research agenda. By doing so, health literacy research will be able to better reflect the changes in today’s health information context (Nutbeam, 2018). This could happen on two levels. First, every new effort to conceptualize, measure, or address health literacy as a broader construct could include health information appraisal. Second, new streams of research could be initiated to specifically address health information appraisal. This would imply first reaching a consensus on a conceptualization and operational definition of health information appraisal, thus achieving a shared understanding of the basic skills and competencies one needs in this context. This could be done, for instance, by systematically building on theories and frameworks from the various disciplines that have dealt with information appraisal (e.g., communication, education, media studies, or argumentation). Researchers should ensure that all relevant stakeholders (citizens, patients, health care professionals, policy makers) are involved in the process to guarantee that the different perspectives are considered and increase validity. With a clear operational definition, it will be possible to develop a measure of health information appraisal to identify the literacy needs of the population. This could inform the design and testing of interventions to build health information appraisal skills, providing citizens and patients with an essential tool through which to be fully empowered in their social lives and in their interactions with the health care system.

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