

Chapter 21

Granting Access to Information Is Not Enough: Towards an Integrated Concept of Health Information Acquisition



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Introduction

The overarching objective of this book is to explore the potential of technology-enabled methods and tools for objective, quantitative assessment and improvement of Quality of Life. This chapter aims at exploring possible ways to enhance both the conceptualization and the measurement of the subdomain of quality of life labeled *opportunities for acquiring new information and skills*. After a brief overview on the definition of the subdomain under investigation and its original measurement, this chapter will present a summary of current studies aiming at the assessment and/or improvement of the variable, making the point for the urgency to find novel ways to conceptualize and measure it. The core of the chapter will be dedicated to the discussion of how research around the concept of *health literacy*, which is conceptually very close to the subdomain of interest and has received major attention within the academic community in the last decades, might inform developments from the point of view of the contents. On the other hand, we will show how current practices in the fields of marketing and computer science could inspire possible

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advancements as regards measurement. The chapter will conclude with the discussion of some of the challenges and opportunities for future research on the topic.

Definition of the Variable “Opportunities for Acquiring New Information and Skills”

The subdomain of quality of life labeled *opportunities for acquiring new information and skills* has been defined by WHO as “a person’s opportunity and desire to learn new skills, acquire new knowledge, and feel in touch with what is going on [...] through formal education programs, or through adult education classes or through recreational activities, either in groups or alone (e.g. reading)”. The subdomain is included in the environmental domain and refers to the individuals’ feeling of being in touch with, and having news of, what is going on around them. The focus is on a person’s chances to fulfill a need for information and knowledge, whether this refers to knowledge in an educational sense, or to local, national or international news, that has some relevance to the person’s quality of life. Depending on one’s specific circumstances, this can be interpreted either broadly (e.g., being up-to-date with “world news”) or in a more limited way (e.g., knowing what is going on in the local community).

The construct is complex, because it comprises both an objective and a subjective dimension. The objective dimension refers to the *possibility* to acquire information in terms, for example, of accessibility of sources of information. These include formal education sources, such as the school system, but also informal ones, for instance family and friends, which in turn can be accessed through different channels and in different formats. The subjective dimension of the subdomain, instead, refers to the individual’s *ability* to satisfy the need of accessing new information and developing new skills.

Current Studies Aiming at the Assessment of the Variable

The questions included in the original WHOQOL-100 instrument are deemed to cover both dimensions of the subdomain. Three questions are used for each dimension, as the two are deemed equally important. Questions are phrased in order to be able to capture all relevant aspects of acquiring new information and skills ranging from world news and local gossip to formal educational programs and vocational training. It is assumed that questions will be interpreted by respondents in ways that are meaningful and relevant to their position in life [1].

Studies observing different population subgroups and cultures used the classical WHOQOL-100, WHOQOL-BREF [2] or other widely spread measures of quality of life such as the Health-Related Quality of Life score (HRQOL) [3]. Findings related to the measurement of acquiring new information and skills are consistent as they show a positive correlation between this subdomain and the educational level

of the individuals in the sample [4]. Findings are mixed in describing the relationship between financial resources and opportunities for acquiring new information and skills, as also very poor subgroups of the population have a positive perception of their environmental quality of life [5].

The studies presented used the classical measurement tools, whose psychometric properties have been consistently proven across cultures, conditions and against other measures [6–8]. A measure of the environmental domain, though, has to keep up with the historical changes, therefore, to reflect what the current environment actually is in terms of offering opportunities to acquire new information and skills. These studies highlight connections with other constructs, and these connections point to another very relevant construct that will be presented in the next section.

Changes in the Information Landscape and the Need to Update the Subdomain

As outlined above, current studies aiming at assessing *opportunities for acquiring new information and skills* still largely rely on the questions included in the WHOQOL-BREF. The instrument, however, was developed based on the original definition of the subdomain, which dates back to 1994 [9]. In the almost 30 years after the development of the instrument, however, a major societal change has occurred: the advent and the global diffusion of the Internet and affordable personal Internet-enabled technologies and its consequences. The magnitude of this change, moreover, makes it something that cannot be neglected by researchers interested in studying this phenomenon and urges them to reflect on possible ways to update both the conceptualization and the measurement of the subdomain to better reflect today's reality. First, the Internet has allowed people worldwide to have access to an unprecedented number of sources of health-related information on virtually every possible topic [10]. Second, the possibility offered to everyone by the new media, independently from background or qualifications, to contribute to the discussion online, has contributed to the “mushrooming” of websites, blogs and social media posts providing unverified information of varying quality [11].

How does this societal change affect the subdomain *opportunities for acquiring new information and skills*? On the one hand, it makes the issue of access to diverse sources and types of information, i.e., the objective dimension of the subdomain, no longer a major problem. If, during its infancy, accessing the Web required the availability of technologies which were not for everyone, with the relatively recent widespread diffusion of smartphones information can be truly considered ubiquitous [12]. On the other hand, however, the widespread diffusion of online communication has created new disparities [13]. One recent concrete example is the declaration of Tedros Adhanom Ghebreyesus, Director-General of WHO at a gathering of foreign policy and security experts in Munich, Germany, in mid-February during the COVID-19 pandemic. The term “*infodemic*” refers to an excessive amount of information about a problem that is viewed as being a detriment to its solution [14]. This example clearly shows how, over the last years, we have witnessed a shift of the

problem from the *availability* of health related information to the more and more essential *ability* of accessing this information [15]. This is not restricted only to the ability to use technology but refers more in general to all the competences needed to make good use of the opportunities the technology has to offer to maximize quality of life. We argue that in such an information landscape, the subjective dimension of our subdomain, namely one's ability to deal with information collected, should become the conceptually predominant dimension, and therefore the most important to assess and potentially improve, if necessary.

Suggested Approach for Quantitative Assessment/ Improvement of the Variable

In order to explore possible ways to improve the conceptualization of the subdomain *opportunities for acquiring new information and skills* we undertook a critical review of the literature in the field of psychology, educational sciences, health communication, technology, and marketing. This effort serves to explore some constructs that in our view are closely related to the subdomain at stake, by giving particular attention to the evolution in the conceptualization and measurement of their main dimensions over the last years, but also to innovative ways offered by technology to measure them and adapt to them. As regards the conceptualization, we will in particular discuss the concept of health literacy and its evolution, also because health literacy has a direct link to empowerment and health behavior and, in the long term, to improved health outcomes and reduced healthcare costs [16, 17]. Research undertaken in the field of marketing and technology will instead be used as a starting point to suggest possible innovative future directions in measurement.

Learning from Health Literacy Research

The individuals' ability to deal with information has been at the center of research in the field of health literacy [18]. We therefore believe that the advancements in this field could provide precious insights on possible future developments of the subdomain, both from a conceptual and a measurement point of view. The concept of health literacy was originally introduced in the 1970s in the context of school education and was initially understood as a set of basic literacy skills (i.e., reading and writing) in the health domain [19]. Following the societal changes outlined above, researchers in the field started to realize that being health literate entailed more than merely being able to access and read health-related information. Already in the early 2000s, Nutbeam proposed a new definition of health literacy, which has three main dimensions. The first dimension is *basic/functional* health literacy and entails having basic skills in reading and writing to be able to function effectively in everyday situations. A second dimension is labeled *communicative/interactive* health

literacy and refers to more advanced cognitive and literacy skills, which, together with social skills, can be used to participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances. The last dimension, critical literacy, entails more advanced cognitive skills that, together with social skills, can be applied to critically analyze information, and to use this information to exert greater control over life events and situations [20]. From here, also following the growing interest in the concept related to the increasing evidence of a link with health outcomes [16], among researchers in the fields of medicine, public health, and health communication, several authors have contributed to expand the breadth of the concept. As a result, all the most recent definitions of health literacy recognize the multi-faceted nature of the concept and the need to include, besides functional skills, the more advanced skills needed to make sense and evaluate the increasingly complex information that is available to the public, including media literacy skills [21].

We believe that the evolution in the concept of health literacy presented above could be useful to inform the refinement of the contents of the subdomain *opportunities for acquiring new information and skills* and to shift the focus from its functional dimension to a more communicative and, what is even more important, a critical one. Besides the considerable efforts that have been devoted to the conceptualization of health literacy however, a significant amount of scholarly attention has also been devoted to the refinement of existing measurement tools and to the development of new ones [22]. In the following, we will describe some of the mostly used instruments in an evolutionary perspective and briefly discuss the current trends and future directions as they have been described in the numerous reviews that have been conducted recently both in the field of health literacy. The most commonly used measures of health literacy, to date, are the Rapid Estimate of Adult Literacy in Medicine (REALM) [23] and the Test of Functional Health Literacy in Adults (TOFHLA) [24]. The first tool measures a patient's ability to pronounce 66 common medical words and lay terms for body parts and illnesses, while the second was developed using actual hospital materials and consists of a 50-item reading comprehension and 17-item numerical ability test. Both measures were developed in the early years of health literacy research. It has now been recognized by experts in the field that these measures do not fully capture the complexity and richness of the concept of health literacy, but are limited to its functional dimension, i.e., the ability to read and understand health-related information [25]. Starting from this consideration, many research groups around the world have started to develop new measuring tools with a broader scope. Examples of such measures are the All Aspects of Health Literacy (AAHLS) [26], the European Health Literacy Survey (HLS-EU) [27], or the Swiss Health Literacy Survey (HLS-CH) [28]. In contrast with the REALM and the TOFHLA, which are commonly considered objective measures as they ask individuals to perform a concrete task, the new measures are mostly subjective. This means that they ask individuals to rate their ability to perform a task. Whereas this evolution has substantially improved the content validity of the measurement, it has been argued that this type of tools do not actually measure actual ability but rather confidence or self-efficacy [21]. Moreover, several authors have

suggested that new tools need to be developed to overcome the limitations of existing health literacy measurement [29]. Overall, despite the advancements in measurement, tools to assess health literacy are still very traditional and do not seem to take advantage, if not in some rare cases, of the possibilities offered by new technologies.

Advancing Measurement Using Insights from Marketing Research

Whereas, from a content perspective, the field of health literacy and its evolution might be a suitable example to learn from, it does not seem to provide useful insights as regards advancing the measurement of the subdomain under investigation.

The field of marketing is a perfect example of how it is now possible both to acquire precious information about the individuals (e.g., by tracking consumers' behaviors) and to tailor information to their needs, preferences, momentary context and abilities. Online Behavioral Advertising (OBA) is also called "online profiling" and "behavioral targeting" [30] and its definitions are multiple in the literature. One of them is the following from the Federal Trade Commission: 'the tracking of a consumer's activities online—including the searches the consumer has conducted, the web pages visited, and the content viewed—in order to deliver advertising targeted to the individual consumer's interest'. This is just one example of the many definitions; however, they all have in common two distinguished components: the monitoring of users' online behavior and the use of the monitoring data to target future advertising. Behavioral monitoring happens through use of software elements called *cookies*, or simply through the information that we give to our social media. In our online activity, everything can be tracked in principle, but also, we are giving out much information on specific channels. On the ground of the data collected the system make predictions of our behaviors and attitude. As a result, we receive advertising that is tailored to the research we made, or even in a more subtle way, we are exposed to contents because we interacted with a post or we just spent more time on it. Because of our actions, be them conscious or not, our network, and our history, we are timely tailored with the contents that are more prone to trigger an intention or even a behavior of ours. Behavioral data are therefore used to predict new behaviors, or even to arouse behavioral change (which usually results in some kind of financial gain for service provider).

This algorithm-driven approach to marketing and advertising is a novelty compared to the classical "one size fit all" mass media advertising, but also compared to the simple targeted advertising made possible by the Internet so far [30–32]. Based on a large amount of data, the algorithm can also become more refined, and be informed by persuasion and communication techniques, that make our behavioral change more likely to happen [31]. OBA can simply be based on our online activity through the more classical devices such as computers, tablets or smartphones, but it can also be using data derived from wearables and other more sophisticated devices. Whatever is able to collect and track data about our daily routine, our device usage or content consumption, can inform the algorithm for tailoring the

content. The ethical and legal considerations about this practice have accompanied the development of the field since its infancy. The regulatory frames of data protection have been developed worldwide also in consideration of this, and the perception of the users towards his data privacy can strongly influence the persuasive effect of OBA practice. However, if this practice is disputable because of its ultimate aims being directed to profit, there is a chance that the mechanism can be exploited for higher purposes such as the ones related to the health and the wellbeing of individuals.

It was already some years ago when scientists were envisioning technologies able to adapt to the health literacy level of an individual [33]. When technologies able to improve user knowledge in specific chronic conditions were already a reality, researchers advocated for intelligent systems able to improve skill deficits in health care and basic literacy skills, such as numeracy through coaching. Beyond the provision of knowledge, they said, technologies could influence other constructs closely related to health literacy, like for instance self-efficacy and motivation for behavioral change using persuasion techniques and counseling agents. Information technologies could also serve to activate low literate individuals during doctor patient encounters by offering a list of questions and issues at hand. Wac's definition of Quality of life technologies goes in this direction when describing its aims [34]. Technologies able to respond to the needs of the user, and particularly at enhancing his/her quality of life are the ones that prove effective in ameliorating health literacy and related constructs.

Despite some first endeavors in this direction, this is not (yet) happening in health, at least on a large scale. Mobile health has exploited behavioral assessment for content tailoring in specific interventions or for self-management of chronic condition [35], but online (neither offline) behavior is not tracked and used in practice to deliver a more understandable health content. It would thus be essential to follow this line within the health domain. This means to keep developing and improving systems that are able to measure needs, preferences, and abilities through the individual actions (e.g., measuring health literacy level through Natural Language Processing or through real world actions) and to automatically adapt the information provided based on this data and the individual's context [36, 37].

Open Challenges and Future Directions

The goal of measuring the entire construct of Quality of Life, the way it is conceptualized by the WHO, is an ambitious one. Every single subdomain of the construct would deserve a separate scale covering all its dimensions, and this is true also when it comes to "opportunities for acquiring new information and skills". Based on our critical review, we conclude that, in the current information landscape, the measurement of this specific subdomain of the environmental domain (opportunities for acquiring new information and skills) should prioritize the subjective component. Indeed, individuals must be able not only to access information but also to appraise it critically. Only that way the new information and the new skills will contribute to enhance quality of life.

Health literacy research has shown that taking into account—and working towards the improvement of—citizens’ and patients’ ability to critically appraise information has several tangible benefits, making it a valuable investment for governments and health institutions. First, it would enable citizens to practice their “right to health”, making healthcare services more available and equitable [38]. Second, but not less important, it would contribute to the containment of healthcare costs, for instance by reducing utilization of non-necessary health services, increasing participation rates to preventive services, or improving compliance with and adherence to treatment plans [16].

While developing systems that are able to assess and collect essential data in order to adapt information to the individual, we should take into account the ethical challenge related to a “tracking” on the one hand, and wrong adaptation effort, on the other hand, which would contribute to an exacerbation of disparities. A system collecting the wrong measures or interpreting one single measurement as an absolute indicator would offer information platforms that are too restricted, in terms of content, to the “predicted” need and preference of the user. Measurement would need to be comprehensive (and valid) not just in terms of constructs and data collected but also in temporal terms. We need to take a longitudinal perspective in order to work on the effective tailoring approach. Beyond that, we can leverage on what the Quantified Self movement has supported so far [39]. By getting to know more and become more aware about ourselves through technologies, we could contribute to develop a self-determined and an highly democratic process.

Conclusion

Our personal digital devices are always with us, are able to track our actions, to collect contextual information, and even to ask us direct questions. We envision a system able to unobtrusively measure important characteristics of an individual (e.g., educational background, emotional state, beliefs, self-efficacy and health literacy level, health behaviors in daily life) in the long run together with environmental information. This way, we could build an highly tailored system, always at hand, that is able to offer information and recommendations that are not just timely but, hopefully, more useful and persuasive, thus effectively and safely contributing to behavior change, better health outcomes and the long term Quality of Life of the individuals.

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