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Expanding Research on Health Literacy: Lessons from Traditional Literacy Studies

As a reflection on the adaptivity of the field of health communication, this paper compares the adaptation process of the concept of health literacy, from its origins in school health education, when it was understood as a set of technical skills, to the most recent developments that have led to very broad conceptualizations, to the historical evolution of the conceptualizations of traditional literacy. The final goal is to gain insight on how the concept of health literacy may evolve in the near future, and to draw some hypotheses. After highlighting the primary similarities and differences between the adaptation processes of the two concepts, it is proposed that it will be necessary to move from one single concept of health literacy to more specific concepts, adapted to the content of different diseases (e.g. cancer) or settings (e.g. hospitals). This adaptation will be crucial in order to gain a deeper understanding of specific health literacy deficiencies and to create and improve both new and existing health communication and education interventions.

Keywords: traditional literacy, health literacy, health communication, adaptivity.

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1. Introduction

Literacy is commonly defined as the ability to read and write (Collins English Dictionary). As underlined by Baumann (1986), the current meanings of the words "literate" and "literacy," referring to the individual ability or the social practice of reading and writing, however, are a relatively recent development. Traditionally the word "literate" was a synonym of "literary," and to speak of a "literate" person in English meant a man of letters, or a person of a literary turn of mind. Only after the late 19th century the term "literacy" began to express the ability to read and write, without necessarily entailing literary interests. The first signs of attention to literacy as a universal phenomenon only date back to the 13th century, with the development of lay education, and to the following centuries, with the first mass literacy campaigns in Europe (Graff 1995). Before these first attempts, the access to written texts was a prerogative of the exponents of the cloth and of few other chosen members of society. During the following centuries, increasing attention has been directed to literacy until, in 1948, the right to education was set forth in Universal Declaration of Human Rights, ratifying its societal importance. In the second half of the last century the discourse around literacy, its conceptual definitions, and its implications evolved further. Literacy has been addressed from many different perspectives: political, social, cultural, educational, and even ideological. During the years, different authors have described literacy as a basic human right, a political tool, a social practice, an emancipatory factor for underserved populations, and as an ideology, respectively (Goody & Watt 1963; Heath 1980; Ong 1982; Street 1984; Freire & Macedo 1987).

The common thread among these approaches is that they do not consider literacy a goal in itself, but rather see it as the basis for positive social transformation, justice, and personal and collective freedom (UNESCO 2004). Early studies assigned an all-powerful role to literacy, describing it as the solution to all problems such as crime, unemployment, poverty, and poor health (Goody & Watt 1963; Heath 1980). Until some decades ago, anthropologists identified the degree of a society's civilization with its degree of literacy (Havelock 1976). Recently the role of literacy has been downsized and it has been argued that it does not automatically generate

socio-economic development (Graff 2005). Nonetheless, a closer look at the links between literacy and such development makes clear that they are complex and manifold. Thus, it is certain that literacy can play an enormous transformative role in the lives of individuals and communities (Ong 1982; Freire & Macedo 1987).

Moreover, despite the widespread acceptance of the crucial role of literacy in development, and the fact that in popular culture it has been seen as one of the most distinctive marks of civilization (Havelock 1976), illiteracy is still a major societal concern in today's world, where there are over one billion illiterate adults (UNESCO Institute for Statistics 2008). Universal literacy remains a major challenge for both developing and developed countries in terms of commitment and action. According to the latest National Assessment of Adult Literacy (NAAL) conducted in the United States in 2003, around 30 million of American adults (14 % of the population) may lack the necessary literacy skills to function adequately in our society (Kutner et al. 2007). Developing countries present even higher illiteracy rates, up to almost 40 % in Africa (UNESCO Institute for Statistics 2008).

These results stress the fact that the issue of literacy is still evolving and far from resolved, and that more research to advance this complex field is needed. In order to continue the tradition of literacy research without missing what others have learned in the past, in this paper we will compare the development of the concept of literacy with one of the most successful adaptations of the concept to appear in the last decades: the concept of health literacy. For this reason, after a short review of the adapting process that has led to the recent development of new literacy concepts, the focus will be shifted to the description of the evolution of the concept of health literacy, identifying similarities and differences. Such an effort will provide us with some insights about the possible directions that the future developments of the concept of health literacy could take.

2. From Literacy to Literacies

In recent years we have faced an unprecedented increase in the flow of information at all levels of our societies. The increase is strictly related to the widespread diffusion of new communication technologies making a

great amount of written and spoken information available to almost all strata of the population. People are faced with information in different forms and about different topics on a daily basis more now than ever before (Viswanath 2005). As a consequence, literacy is becoming, if possible, more necessary than in the past to allow people to make sense of their everyday lives. Moreover, because of the increasing complexity of information in our societies, the traditional basic definition of literacy as the ability to read and write seems to no longer be sufficient. Over the past few decades this has led the conception of literacy to move beyond its simple notion as a set of mechanical skills to a plural notion encompassing the manifold meanings and dimensions of these undeniably vital competences (Lankshear et al. 1997). Such a view recognizes that there are many practices of literacy embedded in different cultural processes, personal circumstances and collective structures. To acknowledge this complexity UNESCO (2004) has recently redefined literacy as the

> [...] ability to identify, understand, interpret, create, communicate, compute and use printed and written materials associated with varying contexts. Literacy involves a continuum of learning in enabling individuals to achieve their goals, to develop their knowledge and potential, and to participate fully in their community and society.

This definition, besides stressing the conception of literacy as more than basic technical skills, also stresses another important aspect, i.e. that the concept of literacy has to be adapted to the context in which it is used.

Over the last few decades researchers have begun to develop new definitions and conceptualizations of literacy adapted to specific contexts, such as health care (Simonds 1974). This adaptation process, which shifts the focus from educational research to other disciplines, is ongoing and has been widely documented in recent scholarly work, arguing that we cannot speak of literacy any longer, but rather of *literacies* (Anstey & Bull 2006; Mackey 2007; Coiro et al. 2008; Nutbeam 2009).

A closer look at some of the new literacy definitions makes clear that the focus of the adaptation process can be on two different dimensions: the context and the content. New conceptualizations, e.g. *cultural literacy* proposed by Hirsch et al. (1987), are the result of an adaptation on both dimensions. In their book, the authors define cultural literacy

as the translinguistic knowledge on which linguistic literacy depends. In their view, literacy is composed of *formal skills* (reading and writing skills, grammar, and syntax) and *specific contents* (knowledge). At the same time, they also stress the importance of considering the existence of a shared national discourse *(culture)* that cannot be fixed once and for all. In the case of other new literacies, however, the adaptation occurs mainly in the content. This is the case of the conceptualizations of *civic* or *political literacy,* where investigators in the field concur on including knowledge of political concepts and facts (Cassel & Lo 1997). Crick & Porter (1978), for example, defined *political literacy* as "the knowledge, skills, and attitudes that are necessary to make a man or woman both politically literate and able to apply this literacy." Similarly, Denver & Hands (1990) defined *political literacy* as "the knowledge and understanding of the political process and political issues which enable people to perform their roles as citizens effectively." Even if a contextual component is implicit (the political system is different in every nation), this is not explicitly pointed out in the definitions. Lastly, the adaptation process can occur, in some cases, primarily within the context. Examples of this include several definitions of *(new) media literacy:* even if in more complex conceptualizations (see Potter 2004), content is taken into account, the main adaptations consist of the application of literacy skills to the navigation of an increasingly complex media context (Rosenbaum et al. 2008; Leaning 2009; Koltay 2011).

As a reflection on the adaptivity of the field of health communication, the evolution of the concept of literacy discussed above will be compared with the adaptation process of the concept of *health literacy* in the paragraphs to follow.

3. Health Literacy: Evolution of the Concept

Health literacy 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 decisions" (U.S. Department for Health and Human Services 2000). The reasons behind the success of the concept of health literacy (Rudd et al. 2007) reside in the fact that nowadays many people find themselves in difficult situations

when confronted with information regarding their health. The quantity of information regarding health issues is indeed overwhelming: newsstands overflow with specialized health, wellness and fitness magazines, health is one of the most popular search items on the Internet, health books head the bestseller lists, television and radio engage in a multitude of health programs and the market is expanding with products that claim added health values. It is therefore often difficult for non-medical persons to be adequately informed about various health issues that are essential to their health status (Viswanath 2005). In addition, several studies have demonstrated that low literacy is associated with several adverse health outcomes (for an overview see DeWalt et al. 2004). According to these authors, illiterate adults are indeed more likely to report use of preventive services less often, while incurring more frequent hospitalization, worse control of chronic diseases (ibid.) and lower health status (Howard et al. 2006; Sentell & Halpin 2006), all of which is reflected in increased mortality (Sudore et al. 2006). Moreover, low literacy skills have been shown to be an obstacle to a good patient-physician relationship, resulting in lower compliance and adherence to treatments (see Williams et al. 2002 for summary view). Health literacy has thus been seen as a powerful resource in improving public health and decreasing the costs of the health system (Eichler et al. 2009).

3.1. Conceptual Models

The notion of health literacy originates in school health education (Simonds 1974), when it was understood as a set of technical skills applied to the health context. From its origins, the concept has undergone a series of adaptations, leading to the more complex Healthy People 2010 definition presented above. This definition already goes beyond basic literacy skills, implicating the ability to understand and implement medical advice and instructions, but to some degree, this is a matter of literacy proper – the ability to read and write – and numeracy, – the ability to understand numbers. This most narrow definition of health literacy is referred to as *functional health literacy* (U.S. Department for Health and Human Services 2000). Most studies and literature reviews speak of functional health literacy, as defined by Healthy People 2010, but several

other models and definitions have been developed during the last decade (Rudd et al. 2007).

First of all other qualities of patients and medical laity in general were added to the concept of health literacy (see Schulz & Nakamoto 2005; Maag 2005). Schulz & Nakamoto (2005), for example, consider health literacy as the sum of skills a person needs in order to adequately inform himself, make appropriate and reasonable decisions regarding his health, and live in a health-conscious manner. These skills are set on different levels: basic reading and writing skills are the basis on which health literacy can develop. Beside these basic skills, the model includes declarative knowledge of health-related topics and the procedural knowledge necessary to enable people to apply it to health-related decisions. At the highest levels we find the integration of knowledge to patterns and the learning of new patterns in order to adapt to discontinuous change. Although the model should not be seen as necessarily sequential, it is easy to imagine that the more skills on one level are acquired or improved, the easier it is for people to move on to the next.

In this extended concept, an individual with an adequate level of health literacy has basic and elaborate knowledge, competencies, learned skills and abilities to take responsibility and to act in a health-promoting way in everyday life. Health literacy further includes the knowledge of whether and when to establish a contact with the health system, how to navigate the system and how to interact with health professionals. Understanding health literacy in this perspective means accepting that health literacy includes a variety of skills like the application of knowledge and (health) system navigation. In this view, Abel & Bruhin (2003) have defined health literacy as the knowledge-based competency for health-promoting behaviours and attitudes including the handling of health information.

Additionally, in other extensions of the concept of health literacy, e.g. the one proposed by prominent defenders of health literacy Nutbeam & Kickbusch (2000), it has been argued that health literacy should not include only individual competencies but must be considered a concept of public health. Health literacy should then not be a quality of medical laity, but of the relationship between individual communication capacities, the health care system, and the broader society (Baker 2006; Rudd

2007). In this view Nutbeam (2000) proposes a conceptualisation of health literacy on three distinct levels: "functional health literacy," reflecting the outcome of traditional health education; "interactive health literacy," referring to the development of personal skills in a supportive environment; and "critical health literacy," reflecting the cognitive and skills development outcomes which are oriented towards supporting effective social and political action, as well as individual action. As it has been pointed out by Berkman et al. (2010), more recently definitions of health literacy have begun to embrace a more ecologically framed conceptual model with an appreciation for the role of language, culture, and social capital (Zarcadoolas, Pleasant & Greer 2006; Nutbeam 2008), and attempts have been made to integrate different perspectives, e.g. the patients', in the definitions (Jordan et al. 2010).

3.2. Measures of Health Literacy

One of the major challenges currently faced by the concept of health literacy resides in the fact that even though several definitions, models, and frameworks of health literacy were proposed, a clear and shared definition of the concept is still missing (Zarcadoolas et al. 2005; Baker 2006; Nutbeam 2000, 2009; Ishikawa et al. 2008; Berkman et al. 2010). As a result, the complexity presented above is not reflected in the existing measuring instruments: only functional health literacy has been operationally defined and, to date, instruments, e.g TOFHLA or REALM, are only able to measure basic reading and writing skills (Davis et al. 1993; Parker et al. 1995). The existing instruments are definitely not sufficient in capturing all the facets of the concept, and no studies thus far have measured the value of health literacy as a broader construct (Baker 2006; DeWalt et al. 2004; Abel 2008; Mancuso 2009).

4. Discussion & Conclusion

From this brief excursus, far from being exhaustive, comparing the adaptation process of the concepts of traditional literacy and health literacy, at least three interrelated considerations which may impact the future developments of health literacy can be drawn.

First, in comparing the evolution processes of the two concepts, it can be noted that the concept of health literacy has been undergoing an adaptation process similar to that of traditional literacy for several years. Health literacy is no longer defined as basic reading and writing skills in the health context, but includes several other more advanced abilities and skills. On the other hand, unlike the concept of traditional literacy, health literacy seems to have adapted only to context (the health system in general and its evolution) and not with regard to content. As we have shown, even if health literacy has become a multifaceted concept, it remains a single and unique concept, inasmuch as it still refers to "health" as a whole, not considering specific conditions (e.g. diabetes) or settings (e.g. hospitals or health insurance). Let us consider the example of a person who is very literate in terms of reading abilities in the healthcare context (functional health literacy), and who can thus perfectly read and make sense of a prescription or a drug label. At the same time, this person may not be adequately literate with regard to a specific condition, e.g. diabetes, or may not know how to navigate the hospital where he is supposed to receive his treatment. This person, thus, despite being health literate, may not have all the necessary knowledge and skills necessary to make the best decision for his health. We can thus conclude that in order to help us predict specific health outcomes (e.g. diabetes management), health literacy research should consider the possibility of developing more specific concepts, one for all relevant health content.

Moreover, and this is the second consideration, an adaptation to a specific content could help to develop and validate more comprehensive measures of health literacy, no longer limited to basic reading and writing skills. In the case of *cultural* or *civic literacy* presented above, specific measures have indeed been developed on the basis of the specific contents to which the concepts refer (West et al. 1993; Pentony et al. 2001; Losh 2006). Similarly, specifying health literacy for a given health content, e.g. cancer, could allow the operationalization of the levels of declarative and procedural knowledge, i.e. the levels above those that have already been operationally defined and measured (Schulz & Nakamoto 2005). In our view, even if we are aware that health literacy cannot be considered only as declarative and procedural knowledge, but should also include more advanced skills, these two levels are the basis to build on for future con-

ceptual and empirical work around the higher levels of health literacy (see Diviani & Schulz, in Press, for an example of an attempt of specification in this direction).

A third and final consideration, strictly related to the first two, is about the role and the importance of knowledge. As seen in the cases of cultural or civic literacy, without content-specific knowledge it is impossible to operationalize the concepts, and consequently to develop valid measures. We are aware that scholars do not even agree on whether knowledge should be considered part of the definition of health literacy (Baker 2006). In our view, in line with Schulz & Nakamoto (2005) and the Institute of Medicine expert panel (Nielson-Bohlman et al. 2004), knowledge should be considered part of the concept of health literacy, inasmuch as it is the necessary basis, together with basic reading and writing skills, to make sense of existing and new information and to develop the higher-level skills necessary to perform more advanced tasks.

In summary, in comparing the evolution of the concept of health literacy with that of traditional literacy, we are able to create an idea of how the concept of health literacy will most likely evolve in the future. In particular, we conclude that to respond to the increasing complexity of the healthcare sector related in part to the diffusion of new technologies, it will be necessary to move from one single concept of health literacy to more specific concepts, adapted to the contents of different diseases (e.g. cancer) or groups of conditions (e.g. chronic conditions).

We assume that this adaptation will be crucial in gaining a deeper understanding of specific health literacy deficiencies and creating and improving new and existing health communication and education interventions.

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