Health literacy and health disparities: A global perspective

Sarah Mantwill and Nicola Diviani

Introduction

Health literacy, defined as ‘[t]he ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course’ (Rootman and Gordon-El-Bihbety, 2008, p 11), has been found to strongly correlate with many of the social determinants of health, eventually contributing to disparities in health. In the US, for example, lower educational attainment, income, as well as minority race and ethnicity, have all been associated with lower levels of health literacy (Kutner et al, 2006).

In contrast to many determinants, such as gender, education or income, health literacy is considered an intervenable factor. Although research is not yet conclusive, there is the strong assumption that, by providing and communicating easily understandable information to low health-literate populations or by teaching them relevant skills (see, for example, Kripalani and Weiss, 2006; DeWalt et al, 2010; Negarandeh et al, 2013), health literacy can be operationalised in ways that allow targeted interventions. Support for this argument comes from studies that have identified health literacy to be a potential mediator between the social determinants of health (including education) and health(-related) outcomes. Health literacy may therefore be an important factor to consider when trying to reduce the impact of social disparities on health(-related) outcomes and eventually to reduce disparities in health (Sentell and Halpin, 2006; Osborn et al, 2011).

Despite this importance, mechanisms that link health literacy to disparities in health are not well explored (Mantwill et al, 2015), particularly not in ways that would allow generalisations across different contexts and countries to be made.

This chapter aims to discuss three interrelated challenges that likely have influenced current research in the field and that are important to consider when investigating the association between health literacy and health disparities across different contexts and on a global level. The first challenge pertains to lack of general consensus on the conceptualisation and measurement of health literacy, which may have prevented more systematic approaches to the study of health literacy and disparities on a more global level and the development of cross-national surveys. The second challenge concerns structural or contextual
factors that are likely to affect both health literacy and health outcomes across different contexts, and should thus be taken into consideration when studying health disparities. The last challenge refers to assumptions on how culture may influence the study of health disparities in diverse populations. Before discussing these challenges, we briefly review some international research efforts to highlight current practices and findings, as well as associated issues relevant to the field.

**Setting the stage: international research on health literacy and disparities**

Research on health literacy has seen increasing fragmentation (Mackert et al., 2015), which has been mainly driven by two factors. The first factor, which will be discussed later in this chapter in more detail, refers to the consistently growing number of conceptualisations of health literacy and subsequent measurements thereof. The second factor has been the relatively recent growth in interest in the concept of health literacy outside of the US. This has undeniably been a crucial development, as it has led to increased recognition of the concept across the world. Yet it has also led to additional conceptualisations and measurements of health literacy, separated from those that have already been developed, and has raised the question of how far results across different contexts are comparable.

Concerning research on health literacy and disparities, the good news is that until today, studies outside of the US could partly confirm that in other countries health literacy may also follow a social gradient. Results from Europe, for instance, have shown that those reporting lower education and lower income or financial deprivation tend to have lower health literacy levels (von Wagner et al., 2007; Connor et al., 2013; Sørensen et al., 2015). This was also partially confirmed in countries across Asia or the Middle East (see, for example, Fadda et al., 2016; Levin-Zamir et al., 2016; Duong et al., 2017). Further, in line with findings from the US, some studies from Europe point to the fact that health literacy levels are generally lower among immigrant populations compared to the native population (Wångdahl et al., 2014; Quenzel et al., 2016; Mantwill and Schulz, 2017).

These are promising findings, yet results should be carefully evaluated for their cross-cultural validity. Although some studies have used (adapted) measures that were originally developed in the US, so far only few measures are available allowing systematic comparisons of health literacy levels, determinants and outcomes across countries. In this regard, the European Health Literacy Survey (HLS-EU) has been a rather recent effort aiming at assessing health literacy across eight European countries (Sørensen et al., 2015). In direct comparison, findings for the different countries were relatively consistent. In all cases, health literacy followed a social gradient, with those being financially deprived or having lower education presenting lower levels of health literacy (Sørensen et al., 2015). Yet, the magnitude of how these factors influenced health literacy levels largely varied across countries. Regarding financial deprivation, for example, the highest difference was found for Poland and the smallest for Spain (HLS–EU Consortium, 2012). A separate
study from Switzerland, which used the same instrument, found that, in contrast to the European study, self-reported social status was negatively associated with health literacy. In addition, most participants showed problematic levels of health literacy (gfs.bern, 2016), thus implying that one of highest educated countries in the world is among the least health-literate countries in Europe.

In the meantime, the HLS-EU has also seen application outside of Europe (see, for example, Duong et al, 2017; Mávita-Corral, 2017). A study from Japan, where the survey was conducted in an online sample, found, in contrast to the European findings, that health literacy not only increased with age, but was also not associated with educational level. Further, overall health literacy levels were significantly lower than in the European study (Nakayama et al, 2015).

Other systematic approaches that would allow comparing health literacy and related disparities across countries are, for example, the International Adult Literacy Survey (IALS), the Adult Literacy and Lifestyle Survey (ALL), or the latest OECD (Organisation for Economic Co-operation and Development) programme, the International Assessment of Adult Competences (PIAAC) (OECD, no date). Even though these surveys were initially not set up to measure health literacy skills per se, they have been used to investigate literacy domains relevant to health literacy. Rudd and colleagues (2004, 2007), for example, developed the Health Activities Literacy Scale (HALS), which was based on the National Adult Literacy Survey (NALS) and the IAL, and assesses skills related to health literacy. Even though widely cited, the HALS has seen limited application outside of the US. To the best of our knowledge, only Australia, Canada, the Netherlands and the US so far have adopted the HALS and have also reported on it (Canadian Council on Learning, 2007; ABS, 2008; van der Heide et al, 2013). Further, no systematic cross-national comparisons have been conducted.

Yamashita and Kunkel (2015) used data from ALL to compare the mediation effects of literacy between education and self-rated health across different countries. Based on a conceptual model (Rootman and Ronson, 2005) that describes the influence of different types of general literacy skills on health literacy, and that are likely to explain the effects of education on health outcomes, the authors investigated prose, document and quantitative literacy. They found that literacy skills mediated the effect of education on health, yet there was substantial variation in the strength of mediation and differences between different types of literacy. Among others, it was found that in the US numeracy skills was an important predictor whereas in Italy prose literacy played an important role. On the other hand, in Norway and Canada, after controlling for covariates, none of the tested dimensions of literacy were associated with self-rated health (Yamashita and Kunkel, 2015).

There is still relatively little consistent knowledge on the distribution and comparability of health literacy levels on a global level and consequently on its association with health disparities. Even though it has been found that health literacy often follows a social gradient across different countries, the extent and in which ways this relationship plays out is by no means clear yet.
Challenge 1: Finding consensus on definitions and measurements

Many researchers in the field agree that current conceptualisations of health literacy are not met with appropriate operationalisation and that the situation is likely to remain as long as no general consensus is found (Pleasant, 2014; Malloy-Weir et al., 2016; see Chapters 1, 2 and 5, this volume). Even though the concept of health disparities and its appropriate assessment have not gone without discussion (Mackenbach and Kunst, 1997; Kawachi et al., 2002; Braveman, 2006), compared to the field of health literacy, matters have been much clearer. In general, there has been an implicit consensus that the term ‘health disparities’, or ‘health inequalities’, refers to differences in health between groups of which one or more are socially worse off than any other group(s). Groups are often operationalised in terms of socioeconomic status, including educational background, occupational status or income (Whitehead, 1992; Braveman, 2006). In the US the term ‘health disparities’ is most widely used to describe ethnic or racial disparities. Outside of the US, however, the term ‘health inequality’ has seen wider application and is mainly used to refer to socioeconomic disparities in health (Braveman, 2006).

Internationally different indicators are used to quantify health disparities, including group comparisons, by calculating general or infant mortality rates. Further, more complex measures are used, such as the Relative Index of Inequality (RII) to identify the extent of socioeconomic disparities in health or the Gini Index as a predictor of health disparities (Wagstaff et al., 1991; Mackenbach and Kunst, 1997; Regidor, 2004; Braveman, 2006).

In contrast to this, the field of health literacy has seen only little consolidation regarding its conceptualisation and measurement. Pleasant, who in 2013 attempted to assess the current state of health literacy efforts on a global level, found that even though in many countries health literacy had become an area of interest to researchers and policy-makers, relatively loose definitions and conceptualisations had also led to increased fragmentation of the field (Pleasant, 2013). For health literacy-related policy activities, see Part 3 in this volume.

Reviewing the international literature, however, reveals that some important and encouraging overlaps between conceptualisations and measurements do exist. Agreement exists on the fact that health literacy is a multidimensional concept, with functional literacy being one of the key dimensions (see, for example, Nutbeam, 2000; Kickbusch, 2009; Sørensen et al., 2012; Schulz and Nakamoto, 2013; see also Chapter 14, this volume). This is also mirrored in the fact that many functional health literacy measures, which were originally developed in the US, have been adapted to be used in other countries (see, for example, Baron-Epel et al., 2007; Jovic-Vranes et al., 2011; Connor et al., 2013; Fadda et al., 2016). However, it is worth mentioning here that many of the disparities in health that we find today may not necessarily (any more) pertain to differences in functional health literacy, but may be due to other dimensions of health literacy, such as critical literacy. Thus, the still large focus on functional
health literacy may oftentimes underestimate the true contribution of health literacy on disparities in health.

To move the field forward and to understand the impact of health literacy on disparities in health on a more global level, it will be important to reach some consensus on key definitions. In particular, organisations that have a stake in understanding the impact of health literacy on health disparities, but also in promoting health literacy among policy-makers as an intervenable factor, will need to find common grounds. Whether it is the World Health Organization (WHO), OECD or United Nations (UN) agencies, all of which have recognised the importance of health literacy (see, for example, Murthy, 2009; WHO, 2016; OECD, 2017), larger organisations will have to take, at least partly, the lead in describing the contribution of health literacy to health disparities on a population-based level and support data collection efforts on a cross-national level. This is not only a question of responsibility, but also of practicality, given that these organisations already drive many of the global data collection efforts on health disparities.

**Challenge 2: Addressing contextual factors**

Research has largely focused on individual factors that are likely to influence health literacy and related disparities. Yet relatively little attention has been paid to assessing, and potentially disentangling, the relationship between structural or environmental conditions and health literacy. Using a social ecological (Golden and Earp, 2012; McCormack et al, 2017) or an integrated social determinants approach (Koh et al, 2010) would support current efforts to address this lack of research. Besides considering disease types and related outcomes, as well as population domains (that is, socioeconomic position, race/ethnicity or gender), an integrated approach would also consider potential risk factors (that is, access to care or environmental risks) and geography (that is, developed vs developing countries) (Koh et al, 2010). Taking such an approach is as much a conceptual, as it is a methodological, issue. From a conceptual perspective, critical appraisal of the influence of social or environmental conditions would not only consider differences in healthcare systems that could explain differences in health literacy levels, but also underlying structural factors that influence individuals’ engagement with appropriate healthcare. For example, in many parts of sub-Saharan Africa priority is still largely given to providing first aid medical assistance or basic healthcare rather than providing access to comprehensive, preventive health services. Thus, by taking risk factors as well as geographical factors into consideration, conceptual pathways that describe exposure to or experience with health services as a potential predictor of health literacy should also describe structural factors possibly causing variability in findings.

From a methodological perspective, assessment tools that operationalise health literacy independently of structural factors, such as general knowledge on disease prevention or screening behaviours, may lack relevance in countries that do not
provide sufficient access to such services. Further, international comparisons based on these measures would become obsolete. Other structural factors, such as access to education or information, should also be taken into consideration. In its essence, lack of sufficient education and subsequent illiteracy is often considered causative to differences in health literacy, especially when assessed with functional health literacy measures. Further, even in cases where sufficient access to education is provided, access to information may still be limited or not available to all. The concept of ‘communication inequalities’ (Viswanath et al, 2015), for example, posits that information is not equally distributed throughout a social system. In line with this, it has been found that individuals at the lower end of the socioeconomic spectrum are less likely to access and use health information and communication technologies (Viswanath and Ackerson, 2011; McCloud et al, 2013; Kelley et al, 2016). Knowing where and how to access and use health information is a key dimension of most definitions of health literacy, and assessments thereof include, for example, questions on difficulties for the respondents to find relevant information. However, not considering potential limitations in access to information related to structural conditions and attributing it to individual factors only may conceal the real cause of differences in health literacy levels.

Investigating the link between health literacy and health disparities requires an approach that takes context-specific factors into consideration (Paasche-Orlow and Wolf, 2007), including structural factors that are likely to affect health literacy skills and the conditions in which they are used. We understand that this is a rather complex issue that needs to be addressed from multiple sides. From a methodological point of view, we suggest two distinct ways to address this issue. The first is to develop and adapt measures to the context they are used in, considering the influence of factors that are likely to shape the distribution of health literacy. Assessing health literacy in certain parts of Africa, as compared to the US, for example, will not only vary in terms of assessment mode (such as the REALM or NVS that have been found to be not equally applicable in different contexts; see Fransen et al, 2011; Fadda et al, 2016), but also regarding its scope and what is considered to be a sufficient level of health literacy. Asking individuals about their information-seeking behaviour or whether they know when to get screened for colon cancer is less relevant to individuals living in deprived areas with no access to such services than to understand when to seek medical care for certain symptoms or how to prevent infectious diseases (see, for example, Taffa and Chepngeno, 2005; Abebe et al, 2010). Using context-specific measures would provide new insights into health literacy and add to a better understanding of where interventions may be needed. Yet the drawback of this approach is that it does not allow a direct comparison of health literacy across different contexts. Therefore, as a second way to address structural factors, we suggest that besides finding consensus on what health literacy should entail and how to operationalise it (see above), additional analysis techniques should be promoted. This can include, for example, multilevel analysis (Diez-Roux,
Health literacy and health disparities

2000), which has seen only limited application in the field of health literacy so far. Including group-level variables (such as country-level factors) with individual-level variables in analyses would allow us to more clearly isolate the relationship between health literacy and health disparities.

**Challenge 3: Disentangling and assessing culture**

There is relatively little doubt about the fact that the distribution of health literacy varies from one culture to another (Nielsen-Bohlman et al, 2004; Batterham et al, 2016). Cultural differences are likely to occur in terms of the distribution of health literacy levels when comparing different regions, countries or language groups to each other. Especially in the context of health disparities research and the associated study of heterogeneous populations, culture is an important factor to consider.

It would be misleading to argue that the concept of culture has not been a matter of discussion in research on health literacy (Zanchetta and Poureslami, 2006; Shaw et al, 2009; Singleton and Krause, 2009). However, operationalisation of the concept has remained limited, focusing mostly on differences by race or ethnicity, country of origin or native language (see, for example, Sentell et al, 2013; Ng and Omariba, 2014; Mantwill and Schulz, 2017). Using these broad categories may not be sufficient to make any assumptions about cultural practices. Culture is much more than a racial category. On the individual level culture is characterised by its dynamic and continuously changing nature. It is learned through language use, socialisation processes and individual adaptation to environmental conditions. Culture influences the individual’s emotional and behavioural responses to the environment and influences how one’s social network responds in turn. Reducing culture to a broad categorical or dichotomous variable, especially in multicultural societies where population groups and individuals undergo continuous change, may conceal much of the underlying dynamics and intragroup variations (Kagawa Singer, 2012).

For the field of health literacy, the concept of culture is particularly relevant as measurements tend to largely reflect Western biomedical perspectives, including the description of what constitutes an appropriate level of health literacy, thus leaving little room for cultural-specific practices that may be considered appropriate responses to health issues in other cultures. For example, in some cultures, seeking spiritual help or using traditional remedies when confronted with a health threat may be considered a complementary, if not even a substantial, part of coping and treatment. Yet, from a Western biomedical perspective, these practices may be considered to negatively affect coping behaviour and overall health outcomes (Kagawa Singer, 2012).

An additional methodological concern relates to the often quantitative and increasingly self-reported nature of research in health literacy. One of its drawbacks is a lack of understanding in how far responses to different measures are reflective of actual differences in health literacy, or whether they are rather a reflection
of response patterns pertaining to cultural differences. In an earlier mentioned study in this chapter, it was found that participants from Japan, a country with one of the highest life expectancies in the world, scored significantly lower than European participants on the HLS-EU (Nakayama et al, 2015). The authors argued that part of the explanation would lie in the different healthcare systems. Yet we argue that concepts such as self-confidence or self-consciousness may also have influenced response patterns. Research has shown that, in contrast to Western nationalities, Japanese people tend to be more critical of their own behaviour (Heine et al, 2000). Additionally, survey research has found that East Asian people are indeed more likely to indicate lower values on scales than, for example, North American people (Chen et al, 1995; Lee et al, 2002). Explanations for this phenomenon include differences between collectivist and individualist societies that emphasise different values (Chen et al, 1995), or concepts such as explicit self-confidence or self-criticism being more pervasive in some cultures (Heine et al, 2001; Kitayama and Uchida, 2003).

Research on health literacy and disparities is inherently related to the investigation of culturally heterogeneous populations, and must therefore take large variability into account. Culture is a dynamic process that should be considered to shape health literacy throughout the life course in very different ways. Kagawa Singer (2012) recommends a number of steps to enhance research on culture and health disparities, which we believe should be, to a large part, equally considered for research on health literacy. First, researchers considering culture to be an important factor in explaining the relationship between health literacy and disparities need to clearly define and operationalise culture, going beyond simple categorisations. Further, as already partly argued in previous sections, there is a need to further adapt and establish the cross-cultural validity of current measures. This also includes the recognition of the boundaries of those measures, which may not be able to provide a sufficiently nuanced picture of how health literacy varies between cultures and what constitutes a sufficient level of literacy. Last, all this will require more mixed-methods studies to provide more inductive approaches towards the study of culture and its possible association with health literacy and disparities.

Conclusion

This chapter aimed at describing three challenges that may influence current efforts to investigate the relationship between health literacy and health disparities, with a focus on the issue of comparability of findings across contexts and countries. Besides describing potential pitfalls when trying to assess the relationship, the chapter also aimed at highlighting potential solutions. We recognise that the described aspects are often closely interrelated and, at the same time, may often seem to be at two opposite ends of a spectrum. On the one hand, we have discussed how finding a consensus on conceptualisation and definitions would support data collection efforts and comparisons on a more global level. On the other hand,
we have also discussed that research on health literacy and disparities should be context-specific, considering structural (contextual) factors and culture. We believe that these should not be seen as two separate approaches to the study of health literacy and disparities, but rather, as complementary. Agreeing on common grounds would allow more systematic data collection efforts across countries and regions, providing the backdrop for researchers, as well as policy and decision-makers alike, to identify regions at risk for lower health literacy. Further, it would allow a teasing out of the contribution of systemic factors, including those related to the healthcare system as such, and to think about systemic solutions to the problem that may eventually foster equity in health. To respond to the growing call for research and responses to health disparities within countries, which not only pertain to affluent nations (Braveman, 2002), context-specific research on health literacy will be important. Besides disease-related outcomes and individual factors, research will also have to consider cultural and structural factors to support the design of effective programmes and interventions that may help to alleviate some of the health disparities associated with lower levels of health literacy.

References


HLS-EU Consortium (2012) *Comparative report of health literacy in eight EU member states: The European Health Literacy Survey (HLS-EU) (2nd revised and extended version)*.


