Health literacy across the life span: A promising field of interdisciplinary research

Anne-Kathrin Mayer[1]

Abstract

During the last three decades, the concept of health literacy has gained increasing attention in empirical research as well as applied health contexts and political debates. The papers in this volume shed light on the concept of health literacy from different disciplines: psychology, educational sciences, health sciences and public health, communication sciences, and information sciences. The present chapter introduces the topic and gives an overview of the issues addressed. In sum, all papers argue for a broad conceptual understanding of health literacy, incorporating not only basic health knowledge and functional skills but also higher-order motivational and self-regulatory skills which are essential to seeking, evaluating and critically using health information. Regarding the measurement of health literacy, it is argued that more effort should be devoted to developing assessment tools which are applicable in various age groups, taking into account developmental characteristics of the respective groups which guide their understanding of the measures.

1 Introduction

It is undisputed that health is strongly influenced by individual efforts aimed at the promotion of health and the prevention of illness or recovery from diseases. These efforts need to be based on adequate health-related knowledge and skills to be effective. E.g., to prevent obesity, people have to be informed about the calorie content and the nutritional value of foods and about calorie consumption by exercising. To decide which type of treatment they should choose in case of health problems, they need to be able to understand their doctors' recommendations re-

[1] Dr. Anne-Kathrin Mayer, ZPID – Leibniz Institute for Psychology Information, Universitaetsring 15, 54296 Trier, Germany, e-mail: akm@leibniz-psychology.org

lated to the advantages and disadvantages of several alternatives, and possible ask for a "second opinion" or search for additional information to arrive at a decision.

Many health-related decisions, especially those about preventive actions and healthy lifestyles, are made without being in contact with health professionals and are based on information which is systematically sought for or accidentally encountered in everyday life, e.g. in conventional or digital media. However, health-related knowledge of medical laypeople contains lots of misinformation about health. "Myths" about health promotion, medical treatments and other health issues are spread, for example, via newspapers, journals, or websites with health-related content (Kaur, Thapar, Saini, Kaur, & Kaur, 2016). The Internet in particular provides a flood of health information, the amount and complexity of which can lead to "health information overload" (Jiang & Beaudoin, 2016). Because anyone (regardless of his or her level of expertise) can provide health-related content on the Internet, websites, forums, blogs, and social networks contain – besides high-quality information – incomplete, unaudited and invalid information which cannot be realistically assessed by laypeople. Finally, due to ongoing research efforts, empirical evidence in the field of medicine and health sciences is constantly changing. Thus, health-related knowledge that has been built up must always be reflected on and corrected against the background of new findings.

To achieve this, individuals need knowledge, skills and abilities that enable them to obtain reliable and up-to-date information on health issues, to evaluate this information and ultimately apply it to improve their health behaviour and to make appropriate health decisions. Such competences have been subsumed under the label "health literacy" which is basically defined as "a set of cognitive and social skills which determine the motivation and ability of people to gain access to, understand and use information in ways which promote and maintain good health" (Nutbeam, 1998, p. 357). Health literacy is assumed to promote more informed health-related decisions and – mediated by more adequate health behaviours like medical treatment adherence (Miller, 2016); practicing health-promoting behaviours (e.g., exercise or diet; von Wagner, Knight, Steptoe, & Wardle, 2007) or use of preventive services (e.g., cancer screening; Kobayashi, Wardle, & von Wagner, 2013) – indirectly support health and well-being. Numerous studies have provided evidence for the link between limited health literacy and health outcomes (e.g., Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011) or mortality (Smith, Jackson, Kobayashi, & Steptoe, 2018). Moreover, the corresponding causal pathways have been theoretically elaborated systematically (Paasche-Orlow, & Wolf, 2007), and implications for health service practices have been derived (Batterham, Hawkins, Collins, Buchbinder, & Osborne, 2016). From an action-oriented perspective, the promotion of health literacy can be seen as a contribution (although by no means a sufficient prerequisite) to patient empowerment (Schulz & Nakamoto, 2013) and autonomy: Adequate health-related knowledge enables individuals to make more conscious and "informed" health-related decisions.

Over the past three decades, the concept of health literacy has increasingly become the subject of political debate and scientific discourse. As early as 1986, the WHO stressed the important role of prevention and strengthening of health resources within the framework of the "Health for All" programme in the "Ottawa Charter". With the help of health promoting measures, individuals should be enabled to achieve "comprehensive physical, mental and social well-being" (World Health Organization, Regional Office for Europe [WHO-Europe], 1986, p. 1). As central elements of health promotion, the WHO identified information, health-related education and the improvement of social competences and life-practical skills (WHO-Europe, 1986, p. 4). Currently, health-related competencies play a central role in the Health for Growth programme of the European Commission 2014-2020 (European Commission, 2011) and in the Health 2020 framework of the World Health Organization. In addition, regular assessment of health literacy is part of the Eurobarometer. This survey, first conducted in 2014, will focus on digital health literacy, i.e. the search and evaluation of health information on the Internet (European Commission, 2014). The present volume aims at providing some insights into ongoing interdisciplinary research projects on health literacy, considering perspectives from different disciplines, namely psychology, health and communication sciences, information sciences, and educational sciences.

2 Multidisciplinary perspectives on health literacy

In spite of the high prominence of the concept "health literacy", there is still no definite consensus on its conceptualization (e.g. Soellner, Hubert, Lenartz & Rudinger, 2009). Too often, the concept has been defined and operationalized in a quite narrow way as "functional literacy" (Nutbeam, 2000), i.e. basic competences related to reading and understanding verbal and numerical health-related information. This understanding is also underlying international comparative education studies such as PISA (Programme for International Student Assessment; e.g. Klieme et al., 2010), PIAAC (Programme for the International Assessment of Adult Competencies; Rammstedt, 2013) and CiLL (Competencies in Later Life; Friebe, Schmidt-Hertha & Tippelt, 2014). In contrast, current approaches which mainly stem from health sciences and public health research have pointed to the necessity to broaden the concepts' understanding. For the Consortium Health Literacy Project European (HLS-EU), Sørensen et al. (2012, p. 3) examined and aggregated 17 existing definitions of the concept. They arrived at a comprehensive definition of health literacy as "people's knowledge, motivation and competences to access, understand, appraise and apply information to make judgments and take decisions in everyday life healthcare concerning disease prevention and health promotion to maintain and improve quality of life during the life course".

This definition removes the fundamental conceptual distinction between cognitive and behavioral skills on the one hand and their motivational prerequisites

and side effects on the other hand by adding "motivation" to the core of the health literacy concept. However, links between knowledge, attitudes and behaviors are by no means straightforward (e.g., Frisch, Camerini, Diviani; & Schulz, 2012). As stated by Pleasant and Kuruvilla (2008, p. 153) with reference to health knowledge,

> "although knowledge is often considered a prerequisite for change in attitudes and behaviours that lead to better health, that relationship is not always direct, positive, linear or even necessarily present".

The same is true for health-related behavioral skills. For example, people may possess highly differentiated knowledge about healthy diets and the ability to prepare healthy meals. Still, they remain overweight because they do not consume calorie-reduced foods, prefer to have fast food instead of preparing meals or simply eat too much. In addition, it may not be overlooked that available health information will only make its way into people's knowledge structures and health behaviors if individuals are sufficiently motivated to access and process this information. Thus, Peerson and Saunders (2009) argued for a clear distinction of (a) the possession of health information, (b) the understanding of it, and (c) the inclination and ability to act on this information in ways consistent with promoting health. Consequently, four chapters of this volume (Soellner, this volume; Lippke, Preißner, & Whittal, this volume; Huotari, this volume; Schulz, this volume) are devoted to elaborating aspects of the concept "health literacy" and the interrelations of its components, and to demonstrate the usefulness of these more differentiated conceptions for research on health and well-being.

From the perspective of psychology, Soellner (this volume) used a concept mapping approach to derive a comprehensive model of the components of health literacy and their interrelations, including cognitive, behavioral, and motivational facets. In a first step, a number of experts were asked which skills and abilities are beneficial for individuals who want to preserve or improve their health and well-being. The statements they generated were then, in a second step, grouped into meaningful categories by a subsample of experts. Multidimensional scaling and hierarchical cluster analysis of the categorization data resulted in a qualitative model of health literacy which includes, apart from basic skills *(literacy skills* and *health-related knowledge)* and *beneficial personality traits*, several advanced skills and attitudes (e.g., *self-perception*, *information appraisal*, *communication and cooperation)*. This qualitative structural model was used as a starting point for developing a self-report questionnaire of advanced health literacy skills. The questionnaire was applied in samples of adults to validate the model by identifying its factorial structure and examining the associations of health literacy components with well-being and health outcomes. Specific to this model is that perceptive-emotional and motivational components (a proactive approach to one's health, self-perception), and behavioral components (self-regulation, self-con-

trol) – besides the ability to deal with health information and to communicate and cooperate regarding health issues – are included as defining components of health literacy. Aspects related to self-regulation were evaluated by experts as more relevant for health and well-being than the basic health literacy skills that make up the "functional health literacy" concept. An additional empirical study demonstrated that particularly self-regulatory skills were more closely related to indicators of physical and psychological quality of life than more basic literacies.

The chapter by Lippke, Preißner, and Whittall (this volume) stresses the importance of health literacy for changing multiple health-risk behaviors and replacing them with healthier lifestyles, i.e., multiple health behaviors. The authors argue that risk behaviors are often based on a lack of knowledge or on misinformation; thus, fostering health literacy may be considered a key factor in interventions which aim at improving health behaviors. Changes in levels of health literacy may be achieved by provision of information via different channels, by effective measures of health communication and by structured education programs. In a recent review, Nutbeam, McGill, and Premkumar (2017) pointed to the fact that only few studies have been published which are based on a solid theoretical conception and apply adequate research designs and methods. When designing interventions, one has to keep in mind that people differ considerably in their levels of health literacy. In addition, they may profit from different methodological approaches. Thus, personalized intervention programs are needed which take into account individual differences in previous knowledge, competencies, and preferences. Computer-based interventions seem ideal to fulfil these requirements as they allow for individualized, adaptive programs with contents and presentation modalities which are tailored to the individual. Accordingly, it has been demonstrated that health literacy skills may be improved by eHealth and mHealth interventions for people with different health conditions, risk factors, and socioeconomic backgrounds (Brijnath, Protheroe, Mahtani, & Antoniades, 2016; Jacobs, Lou, Ownby, & Caballero, 2016; Watkins & Xie, 2014). Yet, the lack of theoretically-based and methodologically adequate studies led Jacobs et al. (2016, p. 96) to conclude that

> "Before eHealth interventions can be hailed as a behavior change intervention of the future, the effective components and mechanisms need to be identified, rigorously tested, and its cost-effectiveness established in different contexts."

The research by Lippke and her work group provides a valuable contribution to this topic.

Huotari (this volume) takes up the concept of health literacy from the perspective of information sciences, interpreting "health information literacy" as "information literacy in the context of health". In times of ubiquitous availability of health information from multiple sources, especially on the internet, being "health information literate" means more than ever before being able to select the most

adequate information from an almost unmanageable pool of information. As the veridicality and reliability of information varies highly, laypeople need to be able to critically decide which sources of health information are most unbiased, reliable and trustworthy. In addition, the high complexity of medical knowledge often prevents laypeople from understanding the information and making "informed decisions". The latter is not only due to limited understanding of the terms used, but also to the inherent dynamics and contradictions within the scientific field. Against this background, Huotari presents a qualitative and exploratory research approach which aims at examining whether the concept of "cognitive authority" (Wilson, 1983) has the potential to increase the understanding of health information literacy: As argued above, individuals will encounter more irrelevant and/or low quality information in complex and dynamic digital health information environments than in "traditional" information environments. In addition, individuals often do not have the knowledge and experiences to evaluate this information autonomously. Thus, to construct valid health knowledge, they need to decide which sources they ascribe cognitive authority, i.e. which sources may be seen as competent and trustworthy in health issues and, thus, should be turned to for information and advice. In her multidisciplinary CogAHealth project, Huotari aims at examining cognitive authorities of young people in the context of health information. The project qualitatively explores who or what these cognitive authorities are and how they are constructed in the health context. In a first step, Huotari illustrated her approach by showing how the notion of cognitive authority may be used to explain intercultural differences in self-reports of health information literacy among Finnish and Namibian students.

Also drawing on the notion of increasingly complex health information environments, *Schulz* (this volume) points to the problem of "distorted" or even "dangerous" health literacy. He questions a central assumption about the benefits of health literacy, namely that knowledge associated with health literacy is always veridical, adequately understood and processed and leads to more adequate health-related decisions. Besides the questionable and divergent quality of available health information and bias which is caused by search engine algorithms, problems may be exacerbated by user habits. Individuals often selectively and/or uncritically use information accessed on the Internet, or they feel overburdened or unsettled by contradictory information. Inadequate judgements and behaviors may also result from patients' overestimating their expertise or their ability to use health information effectively, particularly in those individuals who lack expertise in dealing with health information and, thus, are unaware of their deficits ("Dunning-Kruger effect"; e.g., Dunning, 2011; Kruger & Dunning, 1999).

3 Assessing health literacy in different age groups

Regarding the assessment of health literacy, most existing instruments aim at assessing individuals' subjective or objective ability to understand, interpret and use health information of different types (verbal, numeric), in different modalities (written – oral) and modes (passive: reading/listening – active: asking or communicating). Among the available self-assessment questionnaires, the HLS-EU-Q is of central importance. The questionnaire was developed within the framework of the Health Literacy Survey of the European Union and was conducted on behalf of the European Commission 2009-2011 (Sørensen et al., 2013). It enables international comparisons regarding the level of health literacy within a network of nine European countries (including Germany). The HLS-EU-Q is based on a model of health literacy that distinguishes four dimensions (access to health information, understanding, assessing and applying health information) which can be expressed in three content areas (disease prevention, health promotion and disease management). The questionnaire comprises 47 questions mapping the 4×3 facets of the model; answers can also be aggregated to form an overall score "health literacy" as well as indices for the four competence dimensions and the three content areas. The questionnaire – as well as its 16-item short form HLS-EU-Q16 (Röthlin, Pelikan & Ganahl, 2013) – has found wide distribution and has also been used in several follow-up studies in Germany (e.g. Jordan & Hoebel, 2015; Tiller, Herzog, Kluttig & Haerting, 2015; Zok, 2014).

The "objective" health literacy tests available to date (e.g. Baker, Williams, Parker, Gazmararian & Nurss, 1999; Davis et al., 1993; Parker, Baker, Williams & Nurss, 1995) usually only cover basic functional literacy (such as the ability to take information on medication side effects from the package insert), but not the ability to plan and carry out a search for information on more complex health topics and to interpret and weight the information gained. All of these methods thus have – at least in samples with a medium and high level of education – clear floor effects and are unsuitable for differentiating between different competence levels. In addition, the basic skills they cover are closely linked to general cognitive abilities. Against this background, it is not surprising that after checking the cognitive functional status, only weak, sometimes even no correlations were found between general health competences and health-related behaviour as well as health outcomes (e.g. Bostock & Steptoe; 2012; Moettus et al., 2014; Zhang, Terry & McHorney, 2014). This even leads Reeve and Basalik (2014) to the conclusion that health literacy (at least in a narrow conceptualization as functional health literacy) represents a redundant construct. Thus, there is a clear need to develop and empirically validate additional tools for the assessment of health literacy. Four of the papers in the current volume contribute to this issue by constructing measures for various age groups from primary school age to old age (Okan & Bollweg, this volume; Firnges, Domanska, & Jordan, this volume; Mayer, Holzhäuser, Chasiotis, & Wedderhoff, this volume; Holzhäuser, this volume) with the aim of

enabling future research on the life-span development of health literacy and its precursors and effects.

This topic is of particular importance as up to now, most research on health literacy has been conducted in adult samples. In younger age groups, the topic has been neglected for a long time. This may be due to the assumption that children and adolescent usually do not assume responsibility for their health; rather, they are dependent on their parents or other adults who make health-related decisions for them and regulate their access to the health system. Results of Firnges, Domanska, and Jordan (this volume) support this assumption. Focus groups meetings with adolescents revealed that the youngsters usually turn to their parents (or sometimes their peers) instead of consulting medical professionals or using information from the internet or conventional media when they experience some health issue and need to make health decisions.

However, interest in children's and adolescent's health literacy is increasing as Okan and Bollweg (this volume) argue based on a systematic and comprehensive literature review. A precondition for research in these age groups is the construction and validation of adequate assessment tools which take into account the cognitive, emotional, and motivational prerequisites of these age groups. Okan and Bollweg (this volume) argue that no gold standard exists for the adequate assessment of the construct in young age groups. Both their paper and the contribution by Firnges et al. (this volume) report work which is designed to fill in this gap by developing assessment tools for children and adolescents. Based on a multimodal construction approach, they place special focus on the subjective perspective of the target group, i.e. their interpretations of questionnaire items which were designed for older age groups. Taking the original version of the well-established HLS-EU-Q as a starting point, both research groups aimed at testing and eventually (re)formulating items in order to make them more relevant and easy-to-understand for the respective age group.

In their interviews and focus groups of 3rd and primarily 4th grade students, Okan and Bollweg (this volume) identified multidimensional and complex perceptions of health. From the children's view, "health" does not only include the absence of illness, but in most of the cases also subjective well-being, i.e. a state of being "happy". In addition, aspects of a "healthy lifestyle", e.g. consuming healthy foods or being physically active, were consistently mentioned in the focus group discussions. Regarding sources of health information, the importance of parents, doctors and teachers was stressed, although children also reported to search actively for information in printed media or on the internet. In sum, these findings suggest that children as young as nine or ten years old have a much more differentiated understanding of health-related concepts than previously assumed. However, children's understanding of the HLS-EU-Q revealed that they are in most cases (as previous researchers have argued) still dependent on their parents when it

comes to dealing with health problems. Based on the described work steps, the authors developed a preliminary version of the HLS-EU-Q for primary school children consisting of $k = 26$ items which refer to finding, understanding, appraising and applying health information. Empirical pilot testing in a large sample of $n = 1{,}000$ fourth-graders from a primary school in North-Rhine Westphalia, Germany will provide information on the validity and reliability of the tool.

Firnges, Domanska, and Jordan (this volume) employed a similar approach to develop, cognitively test and validate an adolescent version of the Health Literacy Survey Questionnaire (HLS-EU-Q47) in their project "Measurement of Health Literacy Among Adolescents" (MOHLAA). By means of cognitive interviews and focus groups discussions, they assessed adolescents' understanding of the HLS-EU-Q47 items as well as their experiences in navigating the healthcare system and managing their health. Theory-driven analysis of the cognitive interviews revealed that adolescents aged 14 to 17 years had only limited understanding of many HLS-EU-Q47 items due to limited cognitive abilities and/or experiences with the healthcare system. Findings from focus group discussions suggest that many adolescents prefer personal health information from family and peers over information from other sources. Thus, an adaptation of item contents to adolescents' experiences with health information and a simplification of item wording with regard to their abilities is required. In addition, the authors argue for the construction of achievement or performance tests to complement subjective assessments of health literacy by objective test data.

This claim is taken up by Mayer, Holzhäuser, Chasiotis and Wedderhoff (this volume) as well as Kuhberg-Lasson (this volume). Mayer et al. stress that self-report questionnaires as perception-based measures of health literacy do not assess abilities, knowledge or skills but represent self-assessments of these constructs which are potentially biased. Unfortunately, existing performance-based measures or achievement tests only capture basic functional literacy (i.e. verbal and numeric skills) or advanced skills relevant to critical health literacy and understanding research. Thus, the contribution by Mayer et al. reports on the development of a standardized test which aims at assessing knowledge related to planning, and conducting health information searches in multiple sources and evaluating their search results. The Health Information Literacy Knowledge Test (HILK) is based on a skill decomposition which was derived from the Big Six-Modell of information literacy skills (Eisenberg & Berkowitz, 1990) and the descriptive Information Problem Solving Using the Internet model (Brand-Gruwel, Wopereis, & Walraven, 2009). A pool of 57 multiple choice-items covering six subskills was pretested, refined and finally reduced to a 24-item version of the test in three studies. In samples of university students, internal consistencies as well as item-total correlations were in the satisfactory range, indicating that the HILK may be used for research purposes. First evidence for the convergent validity of the test was demonstrated by moderate correlations of the HILK with a performance test of

domain-specific scholarly information literacy in the field of psychology and with self-reports of health information literacy. In addition, moderate correlations with tests of fluid nonverbal as well as crystallized verbal intelligence corroborate that the HILK may be interpreted as an ability measure.

Kuhberg-Lasson (this volume) used a refined version HILK in a sample of German vocational school students. In order to make the test more appealing to adolescents and young adults, item content was slightly modified to align it with the lifeworld and interests of these age groups. Particularly, items referring to "healthy ageing" were replaced by ones dealing with "stress management" and well-being. Using this modified HILK, relationships between health information literacy and personal beliefs, sociodemographic characteristics and occupational orientation were examined in a field study with N = 317 students from health-related, commercial, and technical professions. Significant effects of education, domain-specific epistemic beliefs, and health locus of control on health information literacy were found. While health information literacy was independent of gender, age, and vocational orientation, it was higher in vocational students with more advanced level of education, less external health locus of control, and a more pronounced belief that medical knowledge is instable and variable over time. Kuhberg points out how these results may be used to choose objectives for health education, e.g. by challenging students' beliefs in the certainty and stability of medical knowledge, thereby increasing motivation for information seeking and evaluation and supporting the acquisition of health information literacy.

References

Baker, D. W., Williams, M. V., Parker, R. M., Gazmararian, J. A., & Nurss, J. (1999). Development of a brief test to measure functional health literacy. *Patient Education and Counseling, 38(1),* 33-42. doi:10.1016/S0738-3991(98)00116-5

Batterham, R. W., Hawkins, M., Collins, P. A., Buchbinder, R., & Osborne, R. H. (2016). Health literacy: applying current concepts to improve health services and reduce health inequalities. *Public Health, 132,* 3-12. doi:10.1016/j.puhe.2016.01.001

Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., & Crotty, K. (2011). Low health literacy and health outcomes: an updated systematic review. *Annals of Internal Medicine, 155(2),* 97-107. doi:10.7326/0003-4819-155-2-201107190-00005

Bostock, S., & Steptoe, A. (2012). Association between low functional health literacy and mortality in older adults: longitudinal cohort study. *BMJ, 344,* e1602. doi:10.1136/bmj.e1602

Brand-Gruwel, S., Wopereis, I., & Walraven, A. (2009). A descriptive model of information problem solving while using internet. *Computers & Education, 53(4),* 1207-1217. doi:10.1016/j.compedu.2009.06.004

Brijnath, B., Protheroe, J., Mahtani, K. R., & Antoniades, J. (2016). Do web-based mental health literacy interventions improve the mental health literacy of adult consumers? Results from a systematic review. *Journal of Medical Internet Research, 18(6),* e165. doi:10.2196/jmir.5463.