Health literacy and participation in the healthcare of adults: (In)compatible approaches?

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Introduction

The rise of the health literacy movement has coincided with a demand for more patient participation in their own healthcare. Both represent different strategies assigning patients a new role in the responsible management of their own health and involving them in health-related decisions. For both concepts there is no commonly accepted understanding available; instead, the scientific literature provides various concepts and definitions (see Chapter 1, this volume). However, while health literacy basically focuses on the competencies and abilities of patients, participation focuses on patient involvement in the healthcare process.

Some prominent health literacy models conceptualise health literacy as a prerequisite for participation (Sørensen et al., 2012; Squiers et al., 2012), and empirical studies suggest that low health literacy is associated with reduced patient participation and less engagement in shared decision-making, or a rather passive role in health-related decision-making (Collins et al., 2004; DeWalt et al., 2007; Kripalani et al., 2010; Barton et al., 2014; Seo et al., 2016). In this context, a low general health literacy is associated with low socioeconomic status, lower education, migration background, lack of social support and an older age bracket (HLS-EU Consortium, 2012; Toci et al., 2016). However, the localisation of health literacy as an outcome or consequence of the participation process is rarely found (Malloy-Weir et al., 2015; Kamei et al., 2017). Participation is usually exclusively seen as a mediator between health literacy and a health outcome (Paasche-Orlow and Wolf, 2007). However, the evidence basis is still small, so, taking a closer look, it seems that it may be worthwhile to question this assumption and broaden the perspective.

The aim of this chapter is to describe the possible relationship between patient participation and health literacy and the resulting challenges for further development in the context of healthcare. Initially, both concepts are briefly introduced, and possible commonalities and differences highlighted. This is followed by an in-depth examination of the challenges for participation in the care process. The focus is on direct interaction between adult patients, especially
those with low health literacy, and health professionals in healthcare. Building on that, a model is proposed to describe the conceptual relationship between health literacy and participation as enhancing approaches. Finally, opportunities for further development are considered.

**Patient participation in interaction with health professionals: a conceptual approach**

Participation at the micro level of healthcare means the involvement of patients and citizens in decision-making in interaction situations (Collins et al, 2007). This also means the transfer of power and control to the individual. Furthermore, participation addresses taking into account the beliefs, values, preferences and priorities of patients and also addressing the emotional state of the patient (Collins et al, 2007). A key factor in patient participation is the relationship between the health professional and the patient, which is based on partnership. The aim is to establish a cooperative professional relationship in which patients are actively involved in the care process from the beginning (Sahlsten, 2007).

The legitimation of participation is primarily based on normative theory, referring to the implementation of statutory patient rights such as self-determination (WHO, 1994; Thompson, 2007), which are part of national and international charters and legislation. In 1986, the Ottawa Charter, established by the World Health Organization (WHO), called for the promotion of participation and self-determination by patients and citizens in health-related decisions (WHO, 1986). In this context, self-determination rights aim at patients making their own decisions (for example, concerning their own body or the carrying out of examinations and treatments). These decisions may contradict expert opinions or even the views of a social majority. While approaches to self-determination, usually located as a prerequisite for participation, refer to the individual, patient participation is focused on interaction with health professionals (Davies et al, 1997). Furthermore, in utilitarian approaches to the legitimation of patient participation, the positive effects on aspects of health and quality of life are highlighted, which include positive effects on patients’ knowledge and understanding of disease, greater involvement of patients in decision-making and treatment processes, and the reduction of exclusion and discrimination against certain patient and population groups (Joosten et al, 2008; Coulter et al, 2015).

Participation can manifest in various ways, such as physically active participation in care, communicative participation or through social participation (Messer, 2018). Most importantly, participation is about patients being offered the opportunity to decide for themselves, how and to what extent participation should take place, rather than forcing them to achieve a predefined degree of involvement (Ashworth et al, 1992). While various participatory interventions are available, among the most prominent is the shared decision-making concept (Messer, 2018).
Health literacy: from basic literacy to a complex concept

As with participation concepts, health literacy also addresses aspects that can be important for the interaction between patients and health professionals. However, health literacy has undergone a rapid development process, from a basic literacy approach, mostly focusing on reading, comprehension and numeracy, to a complex and multidimensional skill-based concept, focusing on the ability to search, find, understand, evaluate and apply health information, including knowledge and motivation (see Chapters 1 and 14, this volume).

Furthermore, depending on the research traditions, health literacy can either be seen as a risk or an asset, respectively (Nutbeam, 2008). From the perspective of risk-based approaches, low health literacy is a risk factor because a lack of patient skills has a negative impact on the participatory interaction as well as on health outcomes (Nutbeam, 2008). To reduce the risk, health literacy has to be addressed in the clinical process. On the other hand, health literacy as an asset is understood as a resource enabling people to exert greater control over their health and health-related decisions. The focus is on empowering people through specific, needs-based information, training and support (Nutbeam, 2008; Edwards et al, 2009).

The commonalities in these approaches include an emphasis on health literacy as a requirement to maintain access to healthcare, the ability to interact with health professionals and participation in health-related decisions (Batterham et al, 2016). These aspects are mostly relevant at the beginning and during the care process. Thus, the conceptualisation of health literacy as a prerequisite for participation in the interaction with health professionals appears to be obvious (Paasche-Orlow and Wolf, 2007; Ishikawa and Yano, 2008).

Furthermore, it seems that the focus on decision-making processes is one of the central elements of health literacy, which are also central to participation concepts. However, in some prominent health literacy concepts it is not intended to make ‘any’ decision, but rather, an appropriate decision (Nielsen-Bohlman et al, 2004) that has also a beneficial effect on one’s own health (Nutbeam, 1999; Kickbusch and Maag, 2005; Squiers et al, 2012), meaning that the expected decision is already normatively laden. This seems to create its own challenges, so that low health literacy is often associated with reduced patient participation, as described above (Collins et al, 2004; DeWalt et al, 2007; Kripalani et al, 2010; Barton et al, 2014; Seo et al, 2016). Regarding this context, it might be worth taking a closer look on the challenges for those with low health literacy.

Challenges for people with low health literacy to participate in the care process

Robust empirical studies investigating the relationship between health literacy and participation are rare and focus primarily on decisions in the patient–provider relationship. In the following this is examined more closely. It should be noted
that most of the included studies mainly used functional literacy measures to identify people with low health literacy, focusing on reading, comprehension and numeracy (Baker et al, 1996; Parikh et al, 1996; Katz et al, 2007; Wolf et al, 2007; Smith et al, 2009; Aboumatar et al, 2013; Easton et al, 2013; Protheroe et al, 2013; Menendez et al, 2017). However, in this context, one used multidimensional self-assessment health literacy measures (Wigfall and Tanner, 2018), while another one mixed them with functional measures (Ishikawa et al, 2009). Nevertheless, it should be noted that most measurement approaches are criticised due to a lack of validation of the measurement instruments (Pleasant, 2014; Gerich and Moosbrugger, 2016; see Chapter 5, this volume).

Prior to the doctor’s visit, three-quarters of patients with low health literacy in a survey conducted by Aboumatar et al (2013) preferred an active role in decisions about their care (that is, they wanted to make decisions together with their doctor, or alone). There was no statistically significant difference from patients whose health literacy was assessed as adequate (Aboumatar et al, 2013). However, during the doctor’s visit, people with low health literacy seem to experience participatory care less often.

In their scoping review, Malloy-Weir et al (2015) examined the relationship between health literacy and the stages of the individual treatment decision. The included studies are characterised by variable and partly contradictory findings that stimulate questioning of the apparently negatively charged association between low health literacy and participation (Malloy-Weir et al, 2015). The authors concluded that there is no comparability of the available studies. The reasons for this include the heterogeneity of study populations and, importantly, the theoretical problems of the survey measurement instruments for health literacy.

A patient survey in the US also showed no statistically significant difference in the shared decision-making between people who understood health information and those who reported difficulties in understanding (Wigfall and Tanner, 2018). However, the interest in the physician as a source and mediator of information is of particular importance for people with low health literacy (Smith et al, 2009). Further studies have shown that there is also no difference in communication between patients with high and low health literacy during their visits, except that patients with low health literacy ask fewer questions about medical aspects than patients with adequate health literacy, and they less look for additional information (Katz et al, 2007; Ishikawa et al, 2009; Aboumatar et al, 2013; Menendez et al, 2017).

In this context, one has to ask for the underlying reasons for people with low health literacy abstaining from asking questions, and if this puts a strain on patients. Several studies indicate that some patients are afraid of being judged for their questions by health professionals or have already had those experiences (Baker et al, 1996; Parikh et al, 1996; Easton et al, 2013; Protheroe et al, 2013). For example, patients with low health literacy may already have had stigmatising and discriminatory experiences, both within and outside of healthcare (Easton
et al., 2013). Patients with low health literacy often do not even inform their own family about existing problems (Parikh et al., 1996). Out of shame or because they don’t feel able to do so (Protheroe et al., 2013), they refrain from asking in-depth questions or pointing out their problems directly (for example, to mask difficulties in reading or understanding the medical information; see Baker et al., 1996; Parikh et al., 1996; Wolf et al., 2007; Easton et al., 2013). In turn, this impairs their wellbeing, relationship with their health professional and ability to manage themselves in the care process (Easton et al., 2013). Although affected patients wish health professionals to take this into account, they feel a deep sense of shame when they are tested for such problems and the information is kept in their health records, accessible and visible to all health professionals involved (Wolf et al., 2007; Easton et al., 2013). In addition, patients reported that they did not feel they had permission to ask questions; they saw a more passive, wait-and-see behaviour as part of their role, or did not have the desire to ask questions or even discuss the issue with the doctor (Smith et al., 2009; Protheroe et al., 2013). Another aspect is indicated by the finding that some patients, who are more likely to consider their health professional as a paternalistic figure, were satisfied with this situation as it met their expectations (Smith et al., 2009; Protheroe et al., 2013). Nevertheless, they attached importance to a trusting relationship with their doctor, in which they are perceived and respected as a person (Smith et al., 2009).

The reasons patients were not looking for information outside of their doctor’s visit included that they had difficulty reading or understanding written information, felt well informed by their health professionals or simply had no interest in continuing to deal with it (Protheroe et al., 2013). In some cases, they resorted to their own social network as a source of information (Smith et al., 2009; Protheroe et al., 2013). This suggests that they are less critical towards the assessment of the quality of different sources of information (Smith et al., 2009). Patients with low health literacy also report frustrating experiences in navigating the healthcare system (for example, dealing with complicated appointment systems) (Protheroe et al., 2013).

Overall, it cannot be assumed that patients with low health literacy are not interested in active participation. However, they may have other preferences about the form of collaboration with health professionals instead, and these must be negotiated in the participation process. In order to explore further interaction between health literacy and patient participation, it seems helpful to consider the possible significance of the two concepts in the individual phases of healthcare, since people with low health literacy carry their experiences from everyday life as well as their biography into this interaction. At the same time, it may help to examine the phases and situations before and after the interaction with the health professionals. Therefore, in the following, the conceptual relationship between health literacy and participation is discussed.
The conceptual relationship between health literacy and participation: a model design

The earlier presented findings on participation and health literacy indicate that it is difficult to strictly define separate fields in which health literacy and participation can be significant. Figure 40.1 illustrates the possible interaction between health literacy and participation in the healthcare setting. In the following, each of the phases is described in the context of health literacy and participation: (1) dealing with one’s own health; (2) visiting health facilities and contact with health professionals; (3) coping with the disease or the health challenge; and (4) healing or continuation of healthcare. This preliminary model was inspired by the phases of the progression and coping with chronic illness as introduced by Corbin and Strauss (1988) and the models of Ishikawa and Yano (2008) and Kamei et al (2017), aiming at health literacy and participation in healthcare.

Dealing with one’s own health

The person in his or her environment

At the beginning of the process, as presented above, one must consider that the person is socially embedded in his or her own environment (see also Chapter 37, this volume). As such, the person is characterised by needs and values such as physical, social, psychological, spiritual, moral and relational needs. Their everyday life is shaped by various aspects such as work, social relationships, education, religion and biographical experiences.

On a practical day-to-day level, one’s own life can be marked by beneficial and harmful influences on health, such as the health behaviour (for example, smoking, lack of sleep) or external influences that affect the person’s living situation (for example, exposure to fine dust and noise). Nevertheless, at this point, active engagement with one’s own health does not have to be at the forefront of daily life or even an active effort to do something in favour (or against) one’s own health. This is where health literacy comes in, with the aim of preventing the onset of diseases and creating an active awareness of the maintenance and promotion of one’s own health. It is important to note that, prior to entering the healthcare system, the person may have rarely or never had contact with the system before due to health problems.

Health and health problems become significant

An active confrontation with one’s own health can now take place in different ways. On the one hand, in the context of prevention and early detection measures, a person can consider contacting the health system (for example, for vaccinations, dental check-ups). On the other hand, a person can also perceive a change in his or her health status (for example, he or she feels symptoms that cause discomfort).
Figure 40.1: Conceptual relationship between health literacy and participation in the healthcare setting

- Entering the healthcare system
- Visiting health facilities and contact with health professionals
- Coping with the disease or the health challenge
- Withdrawal from the healthcare system

- Dealing with one's own health
- Health literacy
- Participation
- Health and health problems become significant
- The person in his or her environment

- Participating
- Health literacy

- Healing
- Chronification
- Palliative phase/death
It could be the first time or a re-occurrence of a temporary or chronic disease of varying degrees of severity. Each situation poses different challenges for a person to recognise and interpret their complaints and decide whether they require examination or treatment (for example, persistent fatigue, constant thirst; possible self-treatment (and know how to carry it out); or a visit to a health professional (and know the right professional contact person or how to find a suitable health professional in their own environment and to get access). In other cases, if, for example, an emergency situation arises, these considerations must be taken into account much more quickly or other steps taken. This also includes knowing or recognising that a self-treatment attempt beyond the first aid treatment is not appropriate (for example, in the case of signs of a heart attack or stroke).

It is apparent that, in this phase, a person’s health literacy can play a particularly important role in actively entering the healthcare system when dealing with one’s own health. This includes, for example, knowledge and finding information about health protection measures, symptoms and how to contact the right health professional.

Participation is reflected most significantly at the level of social participation (for example, in terms of access to information channels and high-quality information, such as free access to evidence-based information, and also in terms of access to the healthcare system itself).

**Visiting health facilities and contact with health professionals**

If the person enters the healthcare system, this is usually done by visiting a health facility (for example, a doctor’s office or a hospital) and/or by contacting a health professional (for example, a doctor or nursing staff). Additionally, the person now assumes the patient’s role. Depending on the patient’s concerns and state of health, decisions are required related to necessary examinations and treatment, and possibly also regarding nursing and social support. It may be necessary to develop and negotiate lengthy and complex treatment strategies and care packages. Sometimes, however, there is also a reciprocating interplay between the phases (for example, between an examination, self-observation of the patient and a new examination).

The availability and comprehensibility of information, which is a crucial component of health literacy, are also important factors when interacting with health professionals and health facilities. However, the opportunity for participation is particularly important in this phase, including participation in (informed) decision-making and physical participation. In this context, a prerequisite is to focus on the patient’s values, preferences and priorities, and to consider the patient’s living, health and social situations, which may be affected by the individual’s environment as well as experiences of the patient as a person. The health literacy-specific need for independent search, retrieval and evaluation of information by patients should not be necessary (for example, to understand symptoms, a diagnosis or treatment options), as these should now be presented in an understandable way by health professionals.
Coping with the disease or the health challenge

The possible temporary or permanent withdrawal from the healthcare system is linked to coping with the disease or health challenges, but the role of being a patient can be continued. This means that the patient is no longer in direct physical contact with health professionals and/or institutions. However, the healing process or dealing with a chronic illness in everyday life is ongoing, and must now be handled by the patient and his or her relatives in a self-management arrangement (for example, the use of drugs). An interplay with the preceding phase is possible (for example, in complex and protracted treatment processes, such as for oncological or cardiovascular diseases).

In this phase, the importance of available information and the ability to apply these is increasing, and thus the importance of health literacy. Participation plays a major role, especially at the level of social and physical opportunities. It can be assumed that previously experienced participation in decisions on one’s own treatment and the shaping of the life situation can increase the motivation and willingness to apply these.

Healing or continuation of healthcare

If a patient can be cured of his or her health problems, he or she will return to his or her original environment. It may be possible that the person will retain an increased awareness for their own health, at least temporarily. On the other hand, patients with chronic diseases may also enter this phase while being in a symptom-free state of their condition (for example, chronic skin diseases or allergic respiratory problems). However, in the case of severe diseases, persistent need for long-term care or even terminal phases of life, direct contact with health professionals can often remain almost permanently. In this enduring state of patient–provider interaction, it will require a constant exchange of information with the health professional, decision-making and shaping of participation, while all of which will need to be adapted to the changing health conditions of patients.

Résumé

Although this model should be empirically tested and refined in future research, first, it can already be used to highlight three key aspects related to the relationship between health literacy and participation:

• It highlights the different phases of healthcare that a person can pass through and possible linkage as well as the dominating forms of health literacy and participation in each of these phases. This leads to overlaps and phase-wise alternating prioritisations. The greatest overlap lies in direct interaction between patients and health professionals, while at the same time, most of the friction can be located here.
• It emphasises that the person is embedded into his or her environment and biography, which is maintained throughout the entire healthcare system, irrespective of whether it is a matter of a health literacy or participation concept. This is intended to create an awareness that the experience and action of patients in dealing with health and care situations is characterised by a complex, comprehensive context that can only be considered in part in most studies. This ‘daily life’ is characterised by individual priorities (for example, securing livelihoods) and previous experience outside the healthcare sector, such as stigmatising one’s own abilities.
• The model provides an opportunity to comprehend participation also as a prerequisite to facilitate health literacy. This is not based on a linear process, but rather on a dynamic cycle in which both concepts stand in a mutually reinforcing and weakening interplay.

It seems that the interaction between health literacy and participation runs through the entire healthcare system and focuses on overlapping processes. However, empirical findings to date are concentrated on a relatively small part of the system. There are still gaps to be filled in the perspectives. The key challenges that arise are addressed in the following section.

Perspectives for further development

While health literacy primarily addresses how people search, find, understand and evaluate health information (Sørensen et al, 2012), participation goes beyond the individual abilities to deal with health information. Participation focuses on access and interaction in healthcare processes in order to facilitate the involvement of patients in decision-making and their self-determination (Collins et al, 2007).

All this argues in favour of retaining the conceptual separation and sharpening the concept boundaries of participation and health literacy in order to make them empirically comprehensible. Indeed, possible incompatibilities with the health literacy concept seem to appear, which are considered in the following section.

Locating health literacy in further development: a ground-breaking decision

Health literacy is about the prerequisites that a person requires in order to make decisions that promote their own health (Sørensen et al, 2012). It seems to be very common that patients are categorised according to their level of health literacy. There are attributions such as ‘insufficient’, ‘problematic’, ‘sufficient’ and ‘excellent’ health literacy or ‘limited health literacy’ (HLS–EU Consortium, 2012; see Chapter 8, this volume). Such approaches bear the risk of stigmatising affected people and even entire population groups by strongly associate them per se with bad skills (Batterham, 2016). Low health literacy is viewed as a deficit of the patient, suggesting that they only need to learn to become capable in order to navigate through the healthcare system competently. In addition, a decision that
is not the ‘healthiest choice’ from the health professional’s perspective, however, might suit best from the patient’s perspective their overall life situation and wellbeing, seems not to be considered in health literacy concepts. Patients should strive for well-informed, independent and healthy decisions while they are denied the competence to do so in case their decision is not matching a pre-defined health standard. This is somehow contradicting the genuine idea of participation, since the promotion of the patient’s self-determination and freedom of choice, both core principles of available participation concepts, seems not to be possible as intended. In this context, there seems to be a mismatch between the aims of health literacy and participation. Therefore, the link between health literacy and participation cannot be sustained if patients are not offered the freedom of choice to take whatever decision they understand to be the best for themselves.

This chapter highlights that health literacy and participation can be linked, but depending on the health literacy approach, either risk- or asset-based, it seems more or less meaningful, respectively. The risk-based concept facilitates health literacy as a paternalistic approach, aiming at compliance by getting patients to follow recommendations and decisions that health professionals consider appropriate (Nutbeam, 2008). Whereas this approach is already being used in healthcare research and practice, it is somehow contradicting the fundamental idea of participation. The asset-based concept of health literacy instead is much closer to the meaning of participation, as discussed within the scientific literature. Therefore, if the asset-based concept of health literacy was applied in the healthcare context, health literacy and participation could be used as a resource that recognises the right to self-determination and autonomy of patients, and supports patient-centred healthcare. The potential for further development of this kind of ‘health literacy and participation approach’ lies in the proportionate support of people with complex health needs and/or in challenging life situations. This approach would also require considering the complex interplay between the living environment, health context, individual health literacy skills and the abilities of health professionals, all of which influencing the whole care and participation process.

**Enabling patient participation to promote health literacy**

Although participation and health literacy are much debated concepts, to date, their relationship is hardly investigated and not much is known about how or if patient participation may influence health literacy (Malloy-Weir et al, 2015; Kamei et al, 2017). There are some research findings indicating that participation may have beneficial effects on certain health literacy relevant skills, including the improvement of knowledge, an increase in self-perceived control and a better understanding of the disease (Joosten et al, 2008; Coulter et al, 2015; Stacey et al, 2017). However, this assumption has far-reaching consequences on participation processes and the development and delivery of patient information. By letting patients participate, their personal preferences and priorities could be asked for,
and could then support both developing user-friendly and patient-shaped health information as well as their successful uptake by patients. Moreover, including and using patients’ voices in this process would also ensure that information is patient-centred, reliable and shaped to their needs and demands. At the same time, participatory experiences, such as involvement in decision-making, taking part in discussion and mutually determining action, could encourage patients with low health literacy to ask questions and express their needs, wishes and comprehension problems. By supplementing such an approach, health literacy could take greater account of social processes and the classification of information into the subjective realm of life.

**Empowerment of health professionals and health facilities to provide health literacy-based patient information and counselling**

All these trends point to another critical aspect that the health literacy concept should address. Currently, health literacy approaches often involve that responsibility for good or bad health is shifted towards patients. However, the other side of the coin that should also be considered is that health professionals with inadequate communication skills, incomprehensible information material and forms, under-resourced structures in health facilities, complicated access routes and long waiting times for healthcare are, in turn, symptoms of weaknesses of health systems. Patients’ difficulties in finding and navigating their way around should not be attributed to the alleged lack of their skills. Assuming inadequate health literacy in this case hides problems in the health system and leaves people seeking help alone. Therefore, it is also important to consider the limits of the shift in responsibility and its feasibility.

Future research and action should focus more on improving the health literacy of health professionals and health facilities and their responsiveness to participatory approaches. They must be able to provide and communicate information in a way that is tailored to the needs of patients and geared to their abilities and interests. For this purpose, for example, methods of communication such as plain language, teach-back methods and person-centred communication are already available from related areas. In the best case, a compatible promotion of health literacy and participation would lead to the development of more user-friendly health systems and professionals with both aiming to best serve the needs of their patients.

**References**


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