Health literacy in later phases of life: Findings from Germany and other countries

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Background

Societies in the 20th century are ageing, as the proportion of older people in the populations of many countries further increases (UN, 2015; He et al., 2016) – 12 per cent of the world’s population was aged 60 or older in 2015 (UN, 2015). Germany has especially been affected by this development. According to figures from 2015, it has the second oldest population in the world (Federal Statistical Office, 2015; UN, 2015), with one-fifth of its population aged 65 or older (Federal Statistical Office, 2015). Based on current population projections, more than a third of Germany’s population is expected to be at least 65 by 2060 (Federal Statistical Office, 2015). The share of very old people, aged 80 years or older, will further increase, with a doubling of its proportion expected in the next 25 years (Federal Statistical Office, 2015).

In many countries the younger phase of older age (people aged 65–70) is spent in better health, with a compression of expected for this phase (Fries, 1980, 2000). However, in all phases of old age, the risk of health problems, especially chronic conditions, increases (Garms-Homolová and Schaeffer, 2012; WHO, 2014, 2015; Robert Koch Institut, 2015; Lampert et al., 2016).

According to current data, more than half of people aged over 65 in Germany have at least one chronic condition (Nowossadeck, 2012). In addition, older people often suffer from several disorders at the same time, so multi-morbidity is no exception (Anderson and Horvath, 2004). About 70 per cent of people in Germany aged 65–74, and almost 80 per cent of those aged over 75, have at least two chronic illnesses (Robert Koch Institut, 2015). Furthermore, long-term physical and/or cognitive limitations often, but not always, caused by dementia, emerge with increasing age. This puts older people at risk of decreased autonomy (Kuhlmey and Schaeffer, 2008).

All of this shows that older people face the challenge of having to manage adverse health problems in daily life, usually of a permanent nature, and growing increasingly complex over the course of time. They are required to navigate in a more complex health system, deal with a wide range of health-related information,
implement instructions from health professionals, and manage complicated therapy and medication routines (Lorig and Holman, 2003; Müller-Mundt and Schaeffer, 2011; Schaeffer and Haslbeck, 2016). These are only a few of the tasks placed on them, as coping with chronic illnesses is always complex (Williams, 2000; Thorne et al, 2002; Charmaz, 2003; Kralik, 2008; Rijken et al, 2008; Corbin and Strauss, 2010; see also Chapter 12, this volume). Therefore, older people need sufficient health literacy to successfully meet these challenges (Osborn et al, 2010; Berkman et al, 2011; Schaeffer, 2017).

The fact that patients today are assigned a more active part – as emphasised in the debate on the change of the patient’s role (Dierks and Schwartz, 2003; Boyer and Lutfey, 2010; Horch et al, 2011) – reinforces increased demands. Unlike earlier times, patients today cannot behave as passive according to paternalistic concepts, but are instead encouraged to actively participate as consumers and co-producers, to make informed health decisions, and to voice their concerns (Bauer et al, 2005; Schaeffer, 2009; see also Chapter 40, this volume). To be able to fulfil these requirements, health literacy – understood as individuals’ knowledge, motivation and competences to deal with health-related information – is needed, to be able to access, understand, judge, and apply it in order to make health-related decisions (Sørensen et al, 2012, p 3).

Whether older people possess sufficient health literacy, however, is unclear. The aim of this chapter, therefore, is a closer examination of health literacy in the later phases of life. The chapter describes: the prevalence of limited health literacy among older people; the demographic, socioeconomic and health-related determinants associated with limited health literacy among older people; as well as the related health consequences. It is posited that a differentiation of phases in old age is absolutely necessary when considering the health literacy of older people (for more information on elderly people and end of life, see also Chapter 41, this volume).

**Limited health literacy in later phases of life**

First, current empirical findings on the prevalence of limited health literacy in old age are given. We concentrate on findings and results from Europe, and particularly Germany, as they follow different, newly developed, concepts and methods. Health literacy studies concerning older populations usually originate from the Anglo-American region (Zamora and Clingerman, 2011; Chesser et al, 2016; Kobayashi et al, 2016), and examine socioeconomic determinants and health indicators associated with health literacy (Zamora and Clingerman, 2011; Chesser et al, 2016; Kobayashi et al, 2016). These studies consistently indicate a high prevalence of low health literacy in older people. However, the proportion varies depending on sample sizes and measuring instruments used, as well as classifications in terms of age group, which differ to a great extent (Gausman Benson and Forman, 2002; Wolf et al, 2010; Ganzer et al, 2012; Kirk et al, 2012; McDougall et al, 2012; Mosher et al, 2012). In most studies among older people,
Health literacy has been measured with the Wide Range Achievement Test-Revised (WRAT-R), Rapid Estimate of Adult Literacy in Medicine (REALM), Test of Functional Health Literacy in Adults (TOFHLA) and the Newest Vital Sign (NVS) (Zamora and Clingerman, 2011; Chesser et al 2016). Available findings are thus mostly based on a functional understanding of the concept of health literacy (see Chapter 5, this volume).

In addition, population surveys also provide results regarding health literacy in later phases of life (Kutner et al, 2006; ABS, 2008; Rootman and Gordon-El-Bihbety, 2008). They mainly show that older people from the age of 65 and above have significantly lower health literacy than middle-aged adults or younger people. According to the results of the National Assessment of Adult Literacy (NAAL), about one-third of older people lack the sufficient health literacy, for example, to identify an appointment for a medical examination on a leaflet or understand and utilise relevant information on a medical form submitted to them (Kutner et al, 2006). The situation in Canada is similar. The proportion of low health literacy among older people aged 66 or more exceeds 60 per cent (Rootman and Gordon-El-Bihbety, 2008, p 15). In Australia, more than 80 per cent of people aged 65-74 are not sufficiently health-literate (ABS, 2008, p 8).

However, considering these international studies generally reveals that they seldom involve a differentiated examination of older people according to age groups or phases. They mainly only suggest that the proportion of low health literacy increases with age (Baker et al, 2000; Cutilli, 2007; Wolf et al, 2010; Kobayashi et al, 2016), and is higher among the ‘old-old’ than among the so-called ‘young old’. In other words, older people in Anglo-American health literacy studies are usually considered as a homogeneous group.

In Germany and the rest of Europe research on health literacy did not significantly emerge until the European Health Literacy Survey (HLS-EU) was conducted in 2012. The aim was a comparative investigation of the population's health literacy in eight European countries. Based on a systematic literature review a comprehensive definition of health literacy and a corresponding measuring instrument was developed and applied in the participating countries. The results show that the group of older people and, in particular, older people aged 76 or above, have limited health literacy and are among the most vulnerable groups in terms of health literacy; 60.8 per cent of older respondents in that age group have limited health literacy, according to the HLS-EU, and perceive considerable difficulties in dealing with health information (HLS-EU Consortium, 2012).

The European study also provided an insight into health literacy among older people in Germany, although only one of the 16 federal states, the state of North Rhine-Westphalia (NRW), participated. It shows that 53.9 per cent of people older than 76 in Germany (more specifically, in NRW), a slightly smaller proportion compared to the EU average, have a limited health literacy level (HLS-EU Consortium, 2012).

Inspired by the HLS-EU, health literacy studies also began to emerge in Germany. They are all based on its concept and measuring instrument, and
mainly address the general population. One study, originating in Germany, focused exclusively on statutory-insured people (Zok, 2014). The German Health Update (GEDA) conducted by the Robert Koch Institute also collected data on the health literacy of older people. These results indicate that people in later phases of life more often have limited health literacy (Jordan and Hoebel, 2015). In both studies the short version of the HLS-EU questionnaire (HLS-EU-Q16) was used, and therefore presumably might not represent all the health literacy components of importance for older people.

Additionally, only a few investigations on the health literacy of specific population groups in Germany have been conducted thus far (Schaeffer and Pelikan, 2017). Consequently, there are hardly any studies about older people. One such study in NRW focused on young people and older people with and those without a migration background (Quenzel and Schaeffer, 2016). It indicated that older people, especially those with a migration background, have limited health literacy (Quenzel and Schaeffer, 2016). However, this study did not include a differentiated examination of the various age groups. The same applies to a cohort study on cardiovascular risk factors and diseases in the older general population, including data on health literacy (Tiller et al, 2015).

The German Health Literacy Survey (HLS-GER) is of special interest in this context (Schaeffer et al, 2017) – a representative population survey based on the HLS-EU concept. The HLS-GER was conducted in a survey of a total of 2,000 German native speakers from the age of 15 with the help of computer-assisted personal interviews (CAPI) (for further details, see Schaeffer et al, 2016, 2017). Underlying the survey is the conceptual understanding and health literacy definition developed by the HLS-EU Consortium (Sørensen et al, 2012). The study results show that two-thirds of older people aged 65 and above have limited health literacy, that is, they face great difficulties in dealing with health information (Berens et al, 2016; Schaeffer et al, 2016). Age-specific analysis of people aged 65 or older indicates great differences in health literacy among different age groups in old age. It shows that only 4.1 per cent of older people aged between 65 and 70 possess excellent health literacy. Another 30.8 per cent have sufficient health literacy, while more than half (52.5%) have problematic health literacy. Another 11.2 per cent possess an inadequate health literacy level. Consequently, the majority of the respondents perceive great difficulties in dealing with health information (Vogt et al, 2017).

People aged 71-75 can be characterised similarly: here, too, the proportion of inadequate health literacy is roughly 10 per cent. Another 48.6 per cent have problematic health literacy. This value is also approximately equal to that shown by the 65- to 70-year-olds. However, the proportion of excellent health literacy among 71- to 75-year-olds is, at only 2 per cent, slightly lower. Accordingly, only very few older people in this age group find it easy, for example, to understand their physician or to assess the pros and cons of various treatment options.

The results among people aged 76 and older show significant differences. Nearly one-third of the respondents in this age group have inadequate health literacy,
which is almost three times as much as in the younger age groups. Another 45.7 per cent have problematic health literacy. The total share of limited health literacy among respondents aged 76 or above is therefore 75.5 per cent. Hence, health literacy scores differ significantly compared to the two younger age groups \((p<0.001)\) (Vogt et al, 2017). In conclusion, older people generally belong to the vulnerable groups; however, the proportion of limited health literacy is particularly high in the group of the old-old people.

### Limited health literacy and associated factors among older people

As a result of these findings, the question arises as to which determinants are related to low health literacy among older people and explain the high proportions of low health literacy in later phases the main explanatory determinants of low functional health literacy in old age (Chesser et al, 2016). Older people with a migration background and low income tend to have lower health literacy. However, the findings on educational attainment are ambiguous. While the level of education is associated with functional health literacy in some studies (Wolf et al, 2005), no relationship can be established in other studies (McDougall et al, 2012). Also discussed as possible causes for worsening health literacy with increasing age are factors such as the deterioration of cognitive and physical resources, which often manifest in later phases of life (Baker et al, 2002; Cornett, 2006; Howard et al, 2006; Levinthal et al, 2008; Federman et al, 2009; Speros, 2009, 2011; Chesser et al, 2016).

In Europe and Germany empirical findings regarding explanatory determinants of limited health literacy in old age are largely lacking. Initial information is provided by the previously mentioned, age-differentiated, analysis of the HLS-GER (Vogt et al, 2017). This shows that functional health literacy among older people is associated with limited health literacy \((p<0.001)\); 78.7 per cent of all respondents with limited functional health literacy also have limited health literacy. Financial deprivation and the presence of chronic illness are also associated with limited health literacy. For example, almost 80 per cent of financially deprived people older than 65 have limited health literacy. The proportion in the case of older people with chronic illness is at least 70.6 per cent (Vogt et al, 2017).

The results of multivariate analyses show that financial deprivation is the strongest predictor of limited health literacy in old age (Vogt et al, 2017). Looking at different age groups among older people, the results show that financial deprivation remains the strongest predictor in explaining limited health literacy in all age groups among old people (Vogt et al, 2017). Thus, the findings indicate a social gradient.

### Impact of limited health literacy on health

The high proportion of limited health literacy among older people raises the question of health-related consequences associated with this. The existing findings
suggest a link between low health literacy and poor health indicators, with most of these studies mostly being cross-sectional studies that examine functional health literacy and its relationship to health-specific indicators. According to these studies, low health literacy is associated with poorer subjective health (Berkman et al, 2011) and unhealthy behaviours. Older people with low health literacy, for example, more often assess their own health as being poor, and have worse self-management skills (Schillinger et al, 2006; Powell et al, 2007; Wolf et al, 2007; Tang et al, 2008). There are also studies that suggest a link between low health literacy and increased mortality risk among older people (Baker et al, 2000, 2007; Sudore et al, 2006; Cavanaugh et al, 2010; Bostock and Steptoe, 2012). These studies focus on assessment of the functional level of health literacy in the context either of country-specific data on mortality or data generated specially for the studies. Regarding increased mortality risk, however, it must be noted that these investigations do not establish any causal link.

Low health literacy is furthermore related to a more intensive use of health services: emergency care facilities such as hospitals and emergency medical services are used more frequently by older people with low health literacy. By contrast, they make less frequent use of preventive measures and screening examinations (for example, mammography, bowel cancer screening) (Baker et al, 1998, 2004; Scott et al, 2002; Berkman et al, 2011).

Similar findings were obtained in Europe and Germany, but in relation to the general population. Here, too, health literacy is associated significantly with the respondents’ self-assessed health (HLS-EU Consortium, 2012; Jordan and Hoebel, 2015; Schaeffer et al, 2017). People with limited health literacy less frequently assess their state of health as ‘very good’ or ‘good’. Also, a higher prevalence of chronic illnesses, depressive symptoms, severe pain and further persistent health problems among those with limited health literacy have been shown, indicating an association between limited health literacy and behavioural risk factors (Jordan and Hoebel, 2015). Limited health literacy is additionally associated with greater difficulties in orientation within healthcare systems, lacking knowledge about contact points for health problems, and more frequent hospital stays and more intensive use of medical emergency services (Schaeffer et al, 2016).

So far there is little knowledge in Europe and Germany regarding consequences limited health literacy levels have for older people, and especially very old people aged 80 years and above. One study suggests that among people aged 65 and above, health literacy is associated with health-related quality of life and the probability of falling ill with diabetes, stroke among men and heart attack among women (Tiller et al, 2015).

Conclusion

According to available, yet insufficient, findings, older people have a significantly lower level of health literacy compared to the general population. First, they lack
adequate personal skills and competences for accessing, understanding, judging and applying health-related information, for example, to make decisions necessary for maintaining health. Second, the large proportion of limited health literacy indicates the difficulties and complexities of the situational demands placed on the individual, as well as problems communicating with health professions and a healthcare system.

Furthermore, substantial differences between age groups regarding the prevalence of limited health literacy in later phases of life can be shown: people over 76 have especially low health literacy. This is an important result from public health perspective because the likelihood of chronic illness, multi-morbidity and of frailty increases in the phase of old age (Suzman, 2001; Rott and Jopp, 2012; WHO, 2015). At the same time, this involves increased requirements in processing health information. However, personal resources, including health literacy, decrease in old age.

Also noteworthy from a public health perspective is the social gradient related to health literacy among older people. Financial deprivation has been shown to be the strongest predictor of limited health literacy in Germany. This applies particularly to people in later phases of life. This finding is directly linked to discussions on health inequality that have been stressing the great importance of socioeconomic factors for the health of older people for decades (von der Knesebeck, 2008; Lampert et al, 2016). At the same time, the results show that older people with few socioeconomic resources have a higher mortality risk (Huisman et al, 2013), greater functional impairments (Shaw et al, 2014) and a poorer subjective health status (Read et al, 2016). In conclusion, the consequences arising from the findings are discussed. The main points are as follows:

• Although older people and, especially very old people, face great difficulties in dealing with health information, relatively little attention is still paid to them in health literacy research. This urgently needs to be changed.
• It is also necessary to pay more attention to the differences observed among people in different phases of old age that have long been observed in gerontological research. Studies are needed to enable detailed analyses of health literacy among older people. This includes a differentiation between young old, medium old and old people. Such studies should simultaneously close existent research gaps and clarify, for example, how and which health indicators are associated with low health literacy in later phases of life or examine the significance of psycho-social factors.
• At the same time, it is important to promote the development of interventions. Available data – although scarce – already provides an insight into the abilities and skills to deal with health information and provides important approaches for the development of interventions to improve health literacy. One of the main conclusions here is that more attention also needs to be given to age differentiation in the development of interventions.
Likely to be promising for younger old people are interventions aimed at strengthening an individual’s health literacy, and containing elements of information and knowledge communication, as well as strengthening competence (Nutbeam, 2000; Chinn, 2011; see also Chapter 14 and Part 2, this volume). By contrast, in order to strengthen the health literacy of old people interventions aimed at a structural and environmental level seem to be more promising, as in this the phase of life people become more vulnerable in terms of health problems and at the same time lose important personal resources. Thus, approaches aimed at improving the health literacy of the health system, its institutions and professions, and thus reducing the demands placed on individuals, are more important. Initial approaches already exist (for example, health-literate organisations; Brach et al, 2012; Dietscher and Pelikan, 2017; see also Chapters 8 and 31, this volume), and their adaptation to the target group of old people is an important task for the future. This is important, as it is necessary to avoid shifting the problem to the individual instead of changing the structural deficits that only manifest in the individual.

Greater attention should also be paid to increasing inequalities in old age. Interventions need to address not only health literacy, but also the healthcare system needs to be accessible to, for example, financially deprived old people. More importance should be paid to the topic of health literacy at the political level as well. This is emphasised by WHO initiatives such as the Shanghai Declaration (WHO, 2016) or the National Action Plans existing in many countries (Puntoni, 2010; Ministry of Health [NZ], 2015), including in Germany (Schaeffer et al, 2018).

References


