

International Handbook of Health Literacy

Research, practice and policy
across the lifespan



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Contents

List of figures, tables and boxes	ix
Notes on contributors	xiii
Introduction	xxi
Part 1: Research into health literacy: An overview of recent developments	1
<i>The many facets of health literacy: Scoping the current research of theories, concepts and models</i>	
1 Defining health literacy: Exploring differences and commonalities <i>Kristine Sørensen</i>	5
2 From Saranac Lake to Shanghai: A brief history of health literacy <i>Orkan Okan</i>	21
3 Health literacy of children and adolescents: Conceptual approaches and developmental considerations <i>Janine Bröder and Graça S. Carvalho</i>	39
4 The concept of mental health literacy <i>Anthony F. Jorm</i>	53
<i>Measuring health literacy: What, why and how?</i>	
5 Measuring health literacy in adults: An overview and discussion of current tools <i>Andrew Pleasant, Caitlin Maish, Catina O’Leary and Richard Carmona</i>	67
6 Measuring children’s health literacy: Current approaches and challenges <i>Torsten Michael Bollweg and Orkan Okan</i>	83
7 Developing an instrument for measuring the health literacy of adolescents: Lessons learned <i>Christiane Firnges, Olga Domanska and Susanne Jordan</i>	99
8 Measuring health literacy in Europe: Introducing the European Health Literacy Survey Questionnaire (HLS-EU-Q) <i>Jürgen M. Pelikan, Kristin Ganahl, Stephan Van den Broucke and Kristine Sørensen</i>	115

Health literacy, health outcomes and health inequalities: Some empirical findings

9	Health literacy and health disparities: A global perspective <i>Sarah Mantwill and Nicola Diviani</i>	139
10	Health literacy in later phases of life: Findings from Germany and other countries <i>Dominique Vogt, Doris Schaeffer and Eva-Maria Berens</i>	153
11	Critical health literacy for the marginalised: Empirical findings <i>Susie Sykes and Jane Wills</i>	167
12	Health literacy and chronic conditions: A life course perspective <i>Gill Rowlands, Joanne Protheroe, Luis Saboga-Nunes, Stephan Van den Broucke, Diane Levin-Zamir, and Orkan Okan</i>	183
13	Health literacy research in the Nordic Countries <i>Kristine Sørensen and Josefin Wängdahl</i>	199

Part 2: Programmes and interventions to promote health literacy **215**

An overview of interventions and programmes

14	Improving health literacy in clinical and community populations <i>Don Nutbeam and Bronwyn McGill</i>	219
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Interventions and programmes for children and adolescents

15	MEDIA PROTECT: A setting- and parent-targeted intervention for a healthy childhood in the digital age <i>Paula Bleckmann, Hanna Schwendemann, Simone Flaig, Lea Kuntz, Anja Stiller, Thomas Mößle and Eva Maria Bitzer</i>	233
16	Using Photovoice as a participatory approach to promote youth health literacy <i>Paola Ardiles, Marlies Casteleijn, Charlene Black and Kristine Sørensen</i>	247
17	Mental health literacy for refugee youth: A cultural approach <i>E. Anne Marshall and Deborah L. Begoray</i>	261
18	Media health literacy, eHealth literacy and health behaviour across the lifespan: Current progress and future challenges <i>Diane Levin-Zamir and Isabella Bertschi</i>	275

Contents

19	School-based mental health literacy interventions <i>Kathryn Cairns and Alyssia Rossetto</i>	291
20	Health literacy interventions for children or adolescents: An overview and insights into practical applications <i>Andrew Pleasant, Kristen Haven Griffin, Caitlin Maish, Catina O’Leary and Richard Carmona</i>	307
<i>Interventions and programmes for adults and older adults</i>		
21	Health literacy interventions in the delivery of pharmaceutical care <i>Laura J. Sahn, Suzanne McCarthy and Sarah Marshall</i>	323
22	A stated preference discrete choice health literacy intervention framework for the control of non-communicable diseases (NCDs) in Africa <i>Kenneth Yongabi Anchang and Theckla Kwangsa Mbunwe</i>	335
23	Occupational health literacy: Healthy decisions at work <i>Marie Birk Jørgensen and Anne Konring Larsen</i>	347
24	Mental health literacy interventions in adults <i>Anthony F. Jorm</i>	359
25	An empirical perspective on the concept of mental health literacy in the field of families with parental mental illness <i>Kathrin Schulze, Patricia Wahl, Dirk Bruland, Stefanie Harsch and Michael Rehder</i>	371
26	Putting the literacy back into health literacy: Interventions in US adult literacy and English language programmes <i>Maricel G. Santos and Julie McKinney</i>	385
Part 3: Policy programmes to promote health literacy		399
27	Health literacy policies: European perspectives <i>Iris van der Heide, Monique Heijmans and Jany Rademakers</i>	403
28	Developing health literacy policy in Scotland: A case study <i>Graham Kramer, Blythe Robertson, Phyllis Easton and Andrew Pearson</i>	419
29	Health literacy policies: National examples from Canada <i>Sandra Vámos, Irving Rootman, Linda Shohet and Lorie Donelle</i>	435

30	Health literacy policies: National example from Austria – A unique story and some lessons learned from an ongoing journey <i>Peter Nowak, Christina Dietscher and Marlene Sator</i>	453
31	Health literacy policy in Australia: Past, present and future directions <i>Anita Trezona, Emma Fitzsimon and Sarity Dodson</i>	471
32	Health literacy policies: National examples from the United States <i>Julie McKinney and R.V. Rikard</i>	489
33	Health literacy in New Zealand: A tale of serendipity and indigenous health <i>Susan Reid and Carla White</i>	505
34	Health literacy and the school curriculum: The example of Finland <i>Olli Paakkari and Leena Paakkari</i>	521
	Part 4: Future dialogue and new perspectives	535
35	Health-literate healthcare organisations <i>Jürgen M. Pelikan</i>	539
36	Future avenues for health literacy: Learning from literacy and literacy learning <i>Paulo Pinheiro</i>	555
37	The social embeddedness of health literacy <i>Ulrich Bauer</i>	573
38	Children as active participants in health literacy research and practice? From rhetoric to rights <i>Emma Bond and Vanessa Rawlings</i>	587
39	Health literacy practices of adults in an avatar-based immersive social virtual world: A sociocultural perspective of new media health literacies <i>Evelyn McElhinney</i>	601
40	Health literacy and participation in the healthcare of adults: (In)compatible approaches? <i>Melanie Messer</i>	617
41	A lifespan perspective on health literacy: Ageing and end-of-life issues <i>Barbara K. Kondilis</i>	633

Contents

42	Salutogenesis and health literacy: The health promotion simplex!	649
	<i>Luis Saboga-Nunes, Uwe H. Bittlingmayer and Orkan Okan</i>	
43	Health literacy in a social context: A meta-narrative review	665
	<i>Ruth Pitt, Terry Davis, Jennifer Manganello, Phillip Massey, Orkan Okan, Elizabeth McFarlane, Opal Vanessa Buchthal, James Davis, Connie Arnold and Tétine Sentell</i>	
44	Health literacy for all? Inclusion as a serious challenge for health literacy: The case of disability	689
	<i>Uwe H. Bittlingmayer and Diana Sahrai</i>	
45	Capacity building for health literacy	705
	<i>Stephan Van den Broucke</i>	
	Index	721

Health literacy and chronic conditions: A life course perspective

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Introduction

Chronic conditions (otherwise known as long-term health conditions) have been defined as ‘illnesses that are prolonged in duration, do not often resolve spontaneously, and are rarely cured completely’, and which are managed with medication and other treatments (Department of Health and Social Care, 2012). As medical advances and improved healthcare have transformed many life-threatening, acute medical conditions such as cancer, diabetes and acquired immune deficiency syndrome (AIDS) into chronic lifelong conditions, the number of patients suffering from one or more chronic conditions is expanding – chronic diseases account for 86 per cent of the deaths and 77 per cent of the disease burden in Europe (WHO, 2015). And the issue is global: 80 per cent of premature deaths due to chronic diseases occur in developing countries according to data from 2009 (WHO, 2015).

The increasing prevalence of chronic conditions that is currently found in children becomes even more disturbing when considering that its prevalence increases through the life course, peaking among older people. In the UK, 58 per cent of people aged over 60 now have a chronic condition compared to 14 per cent in younger adults. People are increasingly suffering from more than one chronic condition simultaneously (multi-morbidity) (Department of Health and Social Care, 2012). Chronic diseases also have an impact on economies – treatment and care is estimated to take up around £7 in every £10 of total health and social care expenditure in the UK according to data from 2009 (Department of Health and Social Care, 2012).

The aim of this chapter is to explore the associations between chronic conditions and health literacy, both from the perspective of patients and citizens (a cross-sectional view), and through people’s life journey from childhood through to adulthood and old age (a longitudinal view). It considers cultural aspects and the role of biomedicine, health promotion and health literacy in advocating healthy lifestyles to promote health and reduce the likelihood and impact of chronic disease. The chapter concludes with implications for research, practice and policy.

Chronic conditions and health literacy

As populations grow and age, the burden of chronic conditions on people and societies will increase. It has been estimated that 50 million people in Europe are living with multiple chronic conditions, which poses major challenges to healthcare systems. Current health services are predominantly disease-orientated, but as patients increasingly have complex needs spanning multiple medical and social specialities, health and social systems are undergoing a shift towards a more patient-centred approach, with greater empowerment and involvement of the patient and their family in medical decisions, expanding the role of patients and families in disease prevention and management activities (Royal College of General Practitioners, 2018). These concerns point to the need to also include certain health promotion and disease prevention competencies (for example, for promoting, facilitating and sustaining healthy lifestyles) when re-thinking and re-shaping health services.

With this shift in focus, the capacities of patients to promote health, prevent illness and manage any illnesses and care processes become key determinants of health. These skills can be referred to as health literacy, and encompass a wide range of capacities, including basic (functional) literacy and numeracy skills needed for health, language numeracy and social skills to participate in health activities and derive meaning from and apply information for health (interactive skills), and the capacity to critically analyse and utilise information (critical skills) (Nutbeam, 2000) (for more information on the conceptual aspects of health literacy, see Chapters 1, 14 and 36, this volume). People with chronic conditions need these capacities to manage their condition(s) and the associated (and often clashing) treatment regimens and self-management activities. It has been established that lower health literacy is associated with poor health outcomes, less healthy behaviours and lifestyle (Berkman et al, 2011; Sørensen et al, 2015), lower self-assessed health (Berkman et al, 2011; Sørensen et al, 2015), more difficulty in acquiring self-management skills (Berkman et al, 2011; Sørensen et al, 2015; Geboers et al, 2016; Mackey et al, 2016), and less efficient use of healthcare services (Vandenbosch et al, 2016). Findings from the European Health Literacy Survey in 2011 indicate that 12 per cent of the people surveyed have inadequate, and 35 per cent problematic, health literacy (Sørensen et al, 2015). Figures from other countries such as England (Rowlands et al, 2015a) and the US (Rudd, 2007) have shown remarkably similar findings. In all cases there is a marked social gradient and association with other social determinants of health (Rudd, 2007; Australian Institute of Health and Welfare, 2012; Rowlands et al, 2015a; Sørensen et al, 2015; Levin-Zamir et al, 2016a). The growing recognition of the importance of health literacy has been emphasised by the World Health Organization (WHO), which has identified health literacy as a critical determinant of health that empowers individuals, enables their engagement in health and in addressing health equity, and must be an integral part of the skills developed over a lifetime (WHO, 2017).

Self-management and health literacy

The mainstay of treatment for chronic disease is effective support for self-management, which can be defined as ‘the care taken by individuals towards their own health and wellbeing; ... to lead a healthy lifestyle; to meet ... social, emotional and psychological needs; to care for their long-term condition; and to prevent further illness or accidents’ (Department of Health, 2005, p 1). Self-management can include responding to symptoms, managing acute episodes, lifestyle changes, managing the emotional impact of conditions and working effectively with health professionals and other community resources (Clark et al, 1991).

Promoting patient self-management is, however, challenging. Even though a broad range of interventions to support effective self-management of chronic conditions has been designed and implemented, these have not been wholly successful, resulting in only small improvements in health outcomes (May et al, 2014; Panagioti et al, 2014). A recent Cochrane review of self-management education programmes concluded that these conferred ‘little or no benefit’ and recommended that future intervention development should consider patient health literacy to increase effectiveness and to explore issues of health equity (Kroon et al, 2014). The situation is complex, however; a study within the European Union (EU)-funded Diabetes Literacy project (Van den Broucke et al, 2014), exploring the impact on diabetes self-management of various types of programmes (group vs individual vs ICT), showed that the programmes had an effect independent of both the method of administration and the health literacy level of the participants (Vandenbosch et al, 2018). It is likely that these different findings reflect varying intervention designs, with some interventions better tailored to patient capacities, including health literacy (further research exploring this is required).

There is evidence of the association of health literacy and management of chronic disease. For example, Schillinger and colleagues (2002) found that patients with inadequate health literacy were less likely to achieve good glycaemic control and more likely to report complications of diabetes. Other research has shown links between health literacy and chronic disease knowledge, poor self-care, including, for example, inhaler use in patients with asthma and medication adherence (Williams et al, 1998; Kalichman et al, 1999).

Current evidence thus shows that health literacy has a vital role in the management of chronic health problems. Viewing the prevention and management of chronic disease through the ‘lens’ of health literacy can bring new insights into the challenges that people have with understanding their health and how to self-manage to promote health and empowerment. A life course perspective to health and chronic conditions acknowledges the roles that the social and lived environment play throughout life, from pre-conception to old age (Marmot et al, 2008), resulting in the social gradients seen in many chronic conditions.

Health literacy and chronic disease through the life course

Health literacy is dynamic and changes through the life course. These changes are related to changes in cognitive skills, with skills developing in childhood and adolescence (Piaget, 1983) and declining in old age, through normal cognitive decline, mild cognitive impairment and dementia (Ray and Davidson, 2014). That said, chronic diseases are a burden for people throughout life, increasingly beginning in childhood and adolescence (Halfon and Newacheck, 2010; Gore et al, 2011; Vos et al, 2015).

In childhood, chronic illnesses negatively influence children's everyday life and daily activities, and hence healthy development in their life course (Mokkink et al, 2008). Moreover, chronic conditions in children not only affect their own health but also their family's health outcomes and lives (Eccleston et al, 2015). Although the prevalence of chronic conditions in children and adolescents is lower than in adults, in economic wealthy countries there has been a significant shift in disease patterns in the younger age groups from acute to chronic illnesses and conditions worldwide (Schlack et al, 2008; Halfon and Newacheck, 2010; van Cleave et al, 2010). Particularly in Europe, North America and Australia, chronic conditions have limiting effects on physical activities in children and are most commonly associated with allergy, asthma, obesity and painful illness (Eccleston et al, 2015). For example, almost a quarter of US children and young people aged under 17 are affected by a chronic illness (Compas et al, 2012). In African children, the WHO's *World health statistics* (2011a) show that communicable diseases, such as HIV and related diseases, malaria and tuberculosis are among the most prevalent and life-threatening chronic conditions. Further chronic conditions, such as chronic pain, type 1 diabetes or sickle cell disease, are known to be associated with various negative health outcomes in childhood. Regarding chronic pain, the number of schoolchildren suffering from recurrent abdominal pain (RAP) varies between 4 and 25 per cent (Huertas-Ceballos et al, 2008), and various studies conducted between 1998-2012 found that approximately one-third of children in Germany suffer from chronic pain and/or RAP (Ahmad and Grimes, 2011; Albers et al, 2015). These children are at high risk for developing chronic conditions themselves (Hill and Keating, 2015; Hoekman et al, 2015). In addition, children affected by chronic conditions have a higher risk of hospitalisation and higher demands for home health or extensive medical care, which, in turn, decreases quality of life. Among children, risk factors for chronic conditions, such as obesity, which has been shown to be associated with health literacy in children (Shih et al, 2016), are increasing, with a prevalence of nearly a third of children aged 2 to 15 and rising (Department of Health and Social Care, 2017). As a result, chronic conditions such as diabetes, previously only seen in adults, are now being seen in children (Chiarelli et al, 2005). Addressing behaviour and lifestyle factors early in young people can have sustainable effects in their adult life (Gore et al, 2011), making chronic conditions an important target for health promotion and prevention activities as well as for health literacy.

In this context, health literacy skills can be taught from early childhood, and linked with stages of cognitive development (Piaget, 1983); younger children can be taught factual information, while older children can be taught to identify 'hidden', often health-damaging, messages in popular advertising following media health literacy training (Begoray et al, 2013). For more information on health literacy and the cognitive and social development of children, see Chapter 3, this volume.

The potential settings for building such skills are varied and include the classroom and wider school setting (Shih et al, 2016), and family and home settings, the latter of which has the added benefit of engaging parents and siblings (Fairbrother et al, 2016). Parents are also seen as an important intervention target in order to strengthen their adaptive strategies to support children's chronic illness-related behaviours (Logan and Scharff, 2005). An example of an innovative, community-based approach to developing health literacy in adolescents is the 'Bigger Picture Campaign' (The Bigger Picture, nd), a youth-led diabetes prevention social media campaign co-created by the University of California, San Francisco and Youth Speaks. Using social media, young people are encouraged to speak up and combat the lifestyle determinants of the diabetes epidemic. For more information on health literacy-promoting interventions addressing children and adolescents, see Chapters 16, 17 and 20, this volume.

At the other end of the lifespan, people often have to cope with the development of chronic disorders (Department of Health and Social Care, 2012) and with cognitive decline (Ray and Davidson, 2014). Health literacy tends to decline with age – associated with cognitive decline, increased difficulty in seeing and hearing and accentuated among people from minority and deprived backgrounds (Kobayashi et al, 2015). Evidence is emerging, however, that improving health literacy in older people is both feasible and beneficial. The IROHLA (Intervention Research on Health Literacy Among Ageing Populations) project identified 15 programmes focusing on health literacy in older people, with evidence of an impact on chronic diseases and among vulnerable population groups (Brainard et al, 2016). For more information on health literacy and later life, see Chapters 10 and 41, this volume.

In addition to changes through the life course, health literacy changes in relation to stress, such as a diagnosis of a chronic disorder, have an impact on competencies to perform adequate self-management behaviours (Vandenbosch et al, 2018). There is also an association between health literacy and stress in caregivers of people with diabetes (Gibson, 2012), and between health literacy and stress levels in people receiving dialysis for renal failure (Dodson et al, 2016).

On the other hand, stressful life events, both positive (for example, pregnancy) and negative (for example, the development of a chronic condition) can make people more receptive to developing new knowledge and skills. Such 'teachable moments' are 'naturally occurring life transitions or health events thought to motivate individuals to spontaneously adopt risk-reducing health behaviour' (McBride et al, 2003, p 156). The potential of teachable moments is currently

under-explored, although Renkert and Nutbeam (2001) undertook an exploratory study highlighting the potential for building maternal health literacy through antenatal classes.

Also important is the individual and/or community's culture, which modulates social and environmental influences throughout the life course, and thus influences both the risk of developing a chronic disease and capacities to self-manage. The next section of this chapter explores what health literacy brings to our understanding, and potentially to better management, of cultural issues in relation to chronic conditions.

Cultural aspects to health literacy and chronic conditions through the life course

The close association between culture and health literacy has been recognised in chronic long-term disease across the life course. This is witnessed on a variety of levels such as prevention, detection and self-management of illness, and in the use of health services. In chronic disease prevention, culture is a critical determinant of lifestyle, in particular, nutrition, physical activity and tobacco use (Levin-Zamir and Wills, 2012). Changing risk behaviour and supporting lifestyle changes requires culturally appropriate interventions to enhance health literacy. Additionally, self-management of disease or illness requires skills to navigate the healthcare system, filling out forms, sharing information and personal history, locating service providers and engaging in chronic disease management (Tsoh et al, 2016). This may be particularly difficult for immigrants, who are experiencing challenges to perform these tasks when moving to another country and encountering new health systems, and often new cultures. Several studies have explored how people with specific conditions from new immigrant groups are informed and educated about their condition. The significant language and health literacy difficulties they face are frequently exacerbated by cultural barriers and economic challenges to accessing health services (see also Chapter 9, this volume). In addition, people's responses to illness and communication of health needs are culturally determined and may be differently expressed in different cultures and languages, including expressing and articulating fear, pain and anxiety, and how 'sick roles' are defined and responded to. The concept of 'health' as well as 'illness' varies widely across cultural groups (Levin-Zamir et al, 2017). Chronic disease is of particular concern for cultures in transition from a traditional to a Westernised culture. As an example, diabetes has been known to develop when such populations change their daily habits from a physically active to a more sedentary one and eat more refined foods. For such populations, whether or not language is an issue, any information and interventions must to be culture-sensitive to be effective (Levin-Zamir et al, 2016a, b).

The scientific literature exploring health literacy, culture and intervention in chronic disease over the lifespan focuses mainly on specific age groups, particularly children or older people, and specific diseases such as asthma and diabetes (Vamos

et al, 2015). For example, a review of culture-specific interventions for people with asthma showed that culture-specific education programmes for adults and children from minority groups are likely to be effective in improving asthma-related outcomes (McCallum et al, 2016). Future areas of action and research necessary for improving the care of patients with chronic disorders include recognising that communication through language and cultural competency are different, equally important, factors, and that improving both communication proficiency and the cultural competence of healthcare providers and systems is required to improve health and healthcare (Poureslami et al, 2017). More research is needed to explore the impact of culture on health decision-making and health behaviours. With regard to practice, the American Diabetes Association advocates actions to be taken to address health disparities and develop structured interventions that are tailored to ethnic populations' culture, language, religion and literacy skills. Addressing the impact of the social and living environment and culture on the risk of developing chronic conditions and on the skills to self-manage them through the life course requires a health promotion approach (WHO, 2002).

Health literacy and essential skills for promoting health

The impact of culture on health decisions and health behaviours is linked to the adoption of specific lifestyles that influence health or disease, and to self-management. Belloc and Breslow (1972) highlighted the relationship between chronic disease, physical health status and lifestyles such as alcohol intake, smoking and nutrition, with health increasing as the number of good health habits increased. Building on this, the WHO focused on the role of lifestyle in preventing and reducing the impact of chronic (that is, long-term non-communicable) conditions and diseases, and the importance of leadership at all levels in developing the conditions needed for lifestyle promotion to be effective (WHO, 2011b). This includes both policy-level interventions, such as tobacco and alcohol taxation and control, and public health education to promote healthy diets and physical activity in all aspects of daily living. The medical establishment has responded to this by including the promotion of healthy lifestyles into clinical practice; indeed, a new medical specialty entirely focused on this has emerged: 'Lifestyle Medicine' (Mechanick and Kushner, 2016). Of some concern, however, is the focus on negative 'prohibition' rather than positive 'promotion' messages, which may reduce effectiveness.

Health literacy develops over the life course (Sørensen et al, 2012) and influences healthy lifestyles (Nutbeam, 2000). The promotion of healthy lifestyles is recognised as crucial for preventing and managing chronic disease, as well as for promoting health. Increasingly, those developing health policies are focusing on how people might be supported to adopt healthier lifestyles, and health literacy is one area of growing interest (WHO, 2013, 2017). Most recently the WHO Shanghai Declaration on health promotion put specific emphasis on health literacy promotion in order to address the improvement of individual health

and empowerment, the United Nations (UN) 2030 Sustainable Development Goals (UN, 2015) and an increase in health equity (WHO, 2017). It is becoming apparent that the relationship between health literacy and lifestyle choices is complex, indicating the need to address health literacy throughout the life course, and to include both the individual and the environment within action frameworks. Indeed, the adoption of healthy lifestyle choices by individuals is strongly associated with education level, as is the response to public health campaigns (Buck and Frosini, 2012), which tend to benefit those who already have the most resources (educational, financial etc), with the unwelcome consequence of widening health inequalities (Buck and Frosini, 2012). On the other hand, when health messages are tailored to people's skills levels, knowledge and action on lifestyle can improve (Tavistock Institute and Shared Intelligence, 2009). Furthermore, as cited above, studies exploring the outcomes of self-management education programmes for patients with diabetes have shown that they can be effective for all patients, regardless of their health literacy level (Kim et al, 2004; Vandenbosch et al, 2016). Epidemiological research indicates that the associations between health literacy and lifestyle are stronger for some lifestyle choices (that is, diet and exercise), and weaker or non-existent for others (that is, smoking and alcohol consumption) (Sørensen et al, 2015; Friis et al, 2016). More research is therefore needed in this area, especially qualitative research on people's lived experience of learning about lifestyles and health, and of making decisions on action. This would enable the development of health literacy, that is, building people's capacities to not only understand but also act on information on lifestyle and wider self-management skills, to reduce their risk of chronic conditions and to better manage them if they occur.

Implications for research, practice and policy

Health literacy has much to offer in the prevention and management of chronic conditions throughout the life course. We have described some research in the area, but more needs to be done, particularly in low-income communities, among migrant communities and in developing countries, where 80 per cent of premature deaths from non-communicable diseases occur (WHO, 2015).

Healthcare practice needs to develop so that it is more person-centred, and adapts to people's clinical, social and health literacy needs (Brach et al, 2012). Successful developments in healthcare practice need to be more widely adopted, and also extend to other areas of people's lives, such as social care (Rowlands et al, 2017). Education is central to developing and maintaining health literacy across the life course, from pre-school and early years teaching that incorporates health and health skills, through to teaching adolescents key skills as they develop into adults and make lifestyle choices that will affect their future, through to adult learning, where skills are maintained (Rowlands et al, 2017). In order to give every child a good start in life, the review of social determinants and the health divide in the WHO European Region specifically highlights that actions

should address early childhood on both the individual, and more importantly, the environmental, levels (Marmot et al, 2012). In this context, parents and parental health literacy are important targets in order to improve not only their own health, but also that of their children and families. Policies that aim to address the issues brought through the increasing burden of chronic disease need to be developed and applied across multiple sectors. ‘Health in All Policies’ (HiAP) have been seen as essential to develop effective and health-promoting systems; there is now a need for ‘Health *Literacy* in All Policies’.

Conclusion

In this chapter we have described the importance of health and education policy, and to a lesser extent, social policy, in building health literacy. Better health literacy might lead to both a lower prevalence of chronic disease, and a reduced impact of chronic diseases when they do occur. However, wider action needs to be taken than merely in health and education, realising the potential impact of policies affecting the workplace and commercial organisations, among many others. Health policies to empower people to live healthily and self-manage chronic diseases will not work unless people can easily incorporate them into their everyday life.

Health literacy is needed for people to have capacities to prevent and support self-management in chronic diseases; it should be operationalised within the context of people’s culture and background (Rowlands et al, 2015b), and increasingly in the digital world (see Chapters 18, 39 and 43, this volume). Using diabetes as an example, adopting a healthy diet and regular exercise can prevent or reduce the risk of diabetes, and can help glycaemic control in people already suffering from the disease (Diabetes UK, nd). To maintain a healthy diet and exercise, people need to understand information from a variety of sources, such as health and commercial sources, to appraise the value of this information for themselves, their families, communities and culture, discuss and negotiate the adoption of new ways of living with health professionals, friends, families and employers, and be able to take action, even in the face of barriers. Health literacy is thus needed throughout life, developing from early childhood and through adolescence, through adulthood, and coping with both positive and negative life events such as birth, bereavement and developing chronic conditions, and increasingly employing health literacy in later life, as people cope with increasing frailty, chronic conditions, and sometimes, cognitive decline. People with low skills who have undertaken health literacy training describe developing such capacities (Tavistock Institute and Shared Intelligence, 2009), and can demonstrate a sophisticated understanding of how information for health is evaluated, barriers to implementation identified and sometimes overcome (Rowlands et al, 2015b). As people are embedded into complex social, ecologic and systemic environments, context-related health literacy interventions should be developed and rigorously evaluated, with a focus on those currently facing the highest burden of chronic

disease. Such an approach will have complementary effects on health action and outcomes, and has much to offer in reducing the burden of chronic disease through the life course.

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