Children as active participants in health literacy research and practice? From rhetoric to rights

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Introduction

This chapter highlights recent developments in health literacy research in childhood and adolescence. It draws on the debates framed in the social studies of childhood and feminist approaches to research in order to critically consider contemporary child health literacy research. Article 24 of the United Nations Convention on the Rights of the Child (UNCRC) states: ‘children have the right to good quality healthcare – the best healthcare possible – to safe drinking water, nutritious food, a clean and safe environment, and information to help them stay healthy’ (UNICEF, 2004). This chapter considers health literacy approaches to research in childhood and adolescence, and considers their appropriateness from a rights-based perspective. It also highlights the important role of Article 12 UNCRC (UNICEF, 2004) – that children have the right to be listened to and have their views respected – to argue that there is a significant dearth of children’s voices in health literacy research, which urgently needs to be addressed: ‘Despite the potential for children to make meaningful contributions to research, many projects continue to displace children on the basis of inferiority, dependence and vulnerability’ (Velardo and Drummond, 2017, p 7).

Much of the research in the health literacy arena is adult-centred, and this chapter explores methodologies that confront the dominance of scientific positivistic approaches. We argue that there needs to be a conceptual shift away from simplistic research approaches that attempt to measure health literacy towards rights-based research approaches in order to improve understanding of health literacy in childhood and to challenge issues of power relations, tokenism and adultist agenda-setting. We contend here that the ideology of meaningful participation in current policy development is often, at best, tokenistic or at worst, completely overlooked in research practice due to both the ethical and practical complexities of undertaking research with children and young people. Paakkari and Paakkari (2012) have argued that there is a need for research that focuses on what it means for a child or young person to be health literate in different contexts (see Chapter 34, this volume). To this end, we suggest, that
creative and respectful approaches for researching sensitive topics that include verbal and non-verbal communication provide methodological frameworks that acknowledge the complexities of doing participatory research with children and young people and celebrate the diversity of children and young people’s everyday lives. The chapter concludes with some suggestions for moving future dialogues for undertaking research with children and adolescents towards new horizons in health literacy research.

Understanding health literacy

Academic interest in health literacy has recently increased (Paasche-Orlow et al, 2010). ‘As a field of research, an approach to improved healthcare, and an important area of policy work, health literacy has experienced significant growth and considerable evolution’ (Pleasant et al, 2015, p 1176). As already discussed elsewhere in this volume, health literacy has attracted considerable attention as a goal of public health and has both impacted on and influenced policy in healthcare settings and healthcare systems (Levin-Zamir and Peterburg, 2001). According to Kickbusch (2008, p 104), ‘health literacy should be and needs to be, an active part of a person’s citizenship and it is a key component of social inclusion.’ Health literacy skills have been defined by the World Health Organization (WHO, 2015, p 12) as: ‘the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health.’

While mother’s literacy was previously afforded to children’s health and indeed survival (Sandiford et al, 1995), the development of health literacy in childhood is well acknowledged as an important vehicle for reducing health inequalities in vulnerable groups and in tackling preventable health problems and diseases. It is important that researchers have a clear understanding of what health literacy means (Levin-Zamir et al, 2011) and, although various definitions and models of health literacy in childhood and adolescence exist, all depict it as a complex and multidimensional construct (Bröder et al, 2017; see also Chapter 3, this volume). In relation to children and young people, health literacy is viewed as a powerful mechanism in overcoming health inequalities. According to Velardo and Drummond (2017, p 5), ‘meeting children’s specific needs arguably includes the delivery of information that can be easily accessed and understood by younger age groups.’ Paakkari and Paakkari (2012, p 146) suggest health literacy as a competency ‘includes a blend of theoretical and practical health knowledge, critical thinking, self-awareness, and citizenship.’

The focus of health literacy interventions in childhood and adolescence is not confined to the healthcare arena but extended to schools and the educational curriculum in the policy agenda (Wu et al, 2010; see also Chapters 2 and 34, this volume). Thus, schools have become a setting for health prevention interventions and also for health education and the development of health literacy skills. The WHO (1999, p 7) goes so far as to highlight schools as settings that are key to
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children’s health and also to adults in that: ‘healthy children who become healthy adolescents are more likely to become healthy adults.’ Interventions focus on health literacy as a learning outcome and an individual competency (Paakkari and Paakkari, 2012). Nutbeam (2000) highlights the key elements of functional, communicative and critical health literacy important for children’s health over the life course, and Sharif and Blank (2010) suggest that higher levels of health literacy are associated with higher levels of self-efficacy in childhood. Bröder et al (2017) further outline the three core dimensions of health literacy in childhood as cognitive attributes, behavioural attributes and affective/conative attributes.

Velardo and Drummond (2017, p 6) argue that ‘the delivery of information that is easily accessible and understood by younger age groups, is likely to play a role in shaping subsequent attitudes and behaviours that typically endure into adulthood.’ Thus, health literacy research to date has, arguably, been underpinned not by conceptualisations of child health per se but actually by adult health or more accurately by preventing adult ill health. Thus children in such contexts have been conceptualised not as *beings* in their own right but unhelpfully as *becoming* adults (James et al, 1998), which has dominated approaches in the limited research to date on health literacy in childhood. This point is exemplified by Driessnack et al (2014, p 165) who argue:

> Researchers are beginning to explore health literacy in adolescents; however, no research is being done directly with children, which is a critical oversight because health-related knowledge, attitudes, and behaviors developed during childhood are increasingly being recognised as foundational, deeply rooted, and resistant to change later, when children become adults.

The social studies of childhood has been instrumental in challenging negative conceptions of childhood for over a decade, and it is well acknowledged in other fields that children and young people need to be seen as citizens in their own right (Hill, 2006), citizens with agency and as active participants rather than objects of research (Greene and Hogan, 2005). Acknowledging children as rights-holders has significant implications for research processes (Lundy and McEvoy, 2011, p 129), and we suggest that it is time that these perspectives also underpinned health literacy research.

**Researching health literacy in childhood and adolescence**

As outlined above, there is a growing interest in the field of childhood health literacy (Ormshaw et al, 2013), yet most research focuses on measuring health literacy and, just as there are differences in health literacy and conceptualisations of health literacy, there have been varying measures of health literacy (Paakkari et al, 2016, p 752). There are a growing number of tools that measure health literacy (Cooper Bailey et al, 2016), as exemplified by the Health Literacy Tool
Shed (see https://healthliteracy.bu.edu), which includes questionnaires that purport to measure the health literacy of children and young people. While it is not our intention here to provide a detailed review of the childhood health literacy literature, as these are available elsewhere (see, for example, Ormshaw et al, 2013; Bröder et al, 2017), it is helpful to consider a few examples and there are various studies undertaken to date.

Sharif and Blank (2010) adopted the use of a Short Test of Functional Health Literacy in Adults (STOFHLA) to ascertain the relationship between health literacy and body mass index (BMI) in childhood with 9- to 12-year-old children. While their findings suggest that there is a significant correlation between higher health literacy and lower BMI, they propose that any measure of health literacy needs to be sensitive to children’s cultural context and developmental stage. Driessnack et al (2014) explored the use of the Newest Vital Sign (NVS) (an evidence-based health literacy screening tool; see Weiss et al, 2005) questionnaire and a single Home Literacy Environment (HLE) question to assess health literacy in children. They concluded that children as young as seven were able to complete the questionnaire in a similar time frame and with a similar distribution of results as adults, and that the tool provided a mechanism for identifying which households are potentially at risk of inadequate health literacy. Trout et al (2014) used both the Rapid Estimate of Adolescent Literacy in Medicine (REALM-Teen; see Davis et al, 2006) and NVS to assess the health literacy of 229 young people in a care setting, and suggest that such a measure may be useful in service planning for young people in care and as a baseline measure for youth health literacy knowledge. They do suggest, however, that these scales were limited in that they do not ‘provide a comprehensive overview of youth health literacy’ and ‘do not provide information on youth’s ability to navigate the healthcare system or specific health knowledge related to prevention and treatment’ (Trout et al, 2014, p 42).

Guntzviller et al (2016, p 155) also used a survey to examine health literacy in 100 young people with Spanish-speaking parents in the US, and found that levels of health literacy were ‘remarkably high’ and that age, self-efficacy and self-reported English language fluency were positively associated with health literacy. They suggest, however:

having an “adequate” health literacy score does not mean that the individual will fully understand health information in all medical conversations – especially if the health information is complex and difficult. (Guntzviller et al, 2016, p 158)

Thus, we need to consider how children access, navigate and make sense of health-related information in their everyday worlds when the research on health literacy that does include children has, to date, been limited to studies that try to objectively measure health literacy (Velardo and Drummond, 2017). There is considerable methodological pluralism (see Hammersley, 2008), with Cooper
Bailey et al (2016, p 4) proposing that ‘the proliferation of tools has been useful in many ways. But at this point, we have a bit of a mess. One of the key justifications for a lot of the instrument development activity was to spur the field to move beyond the limiting aspects of the older instruments.’

Pleasant et al (2015) argue that there is a need in a paradigm shift from measuring health literacy to identify those outcomes of best practice health literacy interventions. They suggest that ‘a more viable approach to increase the utility and use of health literacy research is to better understand the positive effects that health literacy can have on the health and wellbeing of individuals, families, communities, nations and the world’ (Pleasant et al, 2015, p 1177; see Chapter 5, this volume).

We suggest that, drawing on Pleasant et al’s suggestion above, such a paradigm shift also needs to be driven across the field of child health literacy, but is one that is respectfully based on children’s rights rather than hollow academic debate. In order to achieve such a shift and for children’s rights to be acknowledged in research, we need to use ‘methods that make it easy for them to express their opinions, views and experiences’ and ensure that they are ‘protected from harm that might result from taking part in research conducted by researchers who use quality, scientific methods and analysis’ (Beazly et al, 2009, p 370). Therefore, if we are to fully understand the role that health literacy plays in childhood and adolescence, we need to have a broader range of research tools rather than the blunt instrument of the questionnaire. We need to consider how we can enable, empower and support children and young people to develop and critically employ health literacy knowledge and skills in their everyday lives in the present.

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As outlined above, the importance of health literacy in childhood is well recognised and evidenced in World Health Organization (WHO) policy, national health agendas and educational interventions, yet this is arguably rhetorical as there is a dearth of research on children’s perceptions of health literacy (Bröder et al, 2017; Okan et al, 2018), even though it is acknowledged in research that even very young children are involved in their own self-care (Chari et al, 2014):

adult experts to define a concept for children and young people without consulting them to understand there meaning of health literacy, what health-related skills and knowledge, or health behaviours and practices may be important for them in their everyday lives. Moreover, while new perspectives from childhood research consider children and adolescents as active citizens, social agents, and co-constructors of their social worlds, they are a social minority living in a “childhood” with unequal power relations, uneven distribution of rights, and that is mainly constructed by adults. (Okan et al, 2018, p 13)
Velardo and Drummond (2017, p 5) argue for ‘investing in children’s health literacy by working with children to encourage meaning contributions in research and practice.’ Bhagat et al’s (2016, p 1) study provides a good example of how, through involving children (in this case young children) in health literacy research, we can gain a better understanding of children’s own conceptualisations and, as such, ‘address health literacy skills when designing and communicating health messages such that they resonate with children.’ Using open-ended interviews and drawing, Bhagat et al’s (2016) research supports Nutbeam’s (2000) model of different types of health literacy, but more importantly illustrates how health literacy has an impact on how children construct meaning in relation to health information and that, through drawing on their own personal experiences, they are able to engage in critical analysis.

Fairbrother et al (2016) adopted the use of qualitative interviews with 9- to 10-year-old children in the UK, and suggest that this approach enabled a better understanding of how children access health information and the diversity of sources that children interact with. They conclude:

Mobilising and bringing together insights from the Social Studies of Childhood, health literacy and New Literacy Studies also offers exciting possibilities for exploring diverse experiences. How children’s interactions with health messages might vary according to ethnicity, socioeconomic position, gender, digitisation and indeed the globalisation of children’s everyday lives represents fertile ground for future research. Further, while this study has honed in on how children access and understand health information, more work is now needed which explores how the ways in which children make health information meaningful relate to how they use this information in the context of their everyday lives. (Fairbrother et al, 2016, p 483)

Focus groups have been effectively used in health-focused research empowering participants to frame their own experiences in their own terms and for investigating deeper knowledge and understanding about aspects of the topic being researched (Green, 2013). Focus groups are also popular research tool with children, and Hernán-García et al (2015), for example, successfully used focus groups to examine the use of the internet by primary school pupils in Spain.

Using child-centred approaches can open up possibilities and opportunities for children to meaningfully participate in research (Clark and Moss, 2001; Barker and Weller, 2003; Greene and Hogan, 2005; Christensen and James, 2008; Bond, 2014), which includes online and digital methods (Barbovschi et al, 2013; Bond and Agnew, 2015). This includes their participation in research into topic previously deemed too sensitive for them to be included in. Coombs (2017), for example, recently used everyday material objects – stuff in a box – in order to facilitate a range of conversations with children about death; Renold (2017) used art-based methods to explore gender-based violence and bullying with teenage children in research.
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When children are viewed through the children’s rights paradigm, using the CRC [Convention on the Rights of the Child] as a framework for implementation, there are distinct implications for research methods: it requires that children are not only entitled to have their views given due weight in research studies but that the adults working with them ensure that their participation is compliant with the CRC. (Lundy and McEnvoy, 2011, p 140)

In order to enable and engage children and young people in respectful and meaningful ways, there is a need to consider the methodology, methods and approaches that create appropriate spaces and opportunities for engagement (Barker and Weller, 2003; Kellett, 2009). If this is to be achieved, the importance of the UNCRC needs to be more widely and better understood in the health literacy field. In health-focused research dominant organisational structures remain (Holloway and Wheeler, 2013), thus power relations is a key factor to address in the methods and ethical conduct of health literacy research, especially with children and young people. Therefore, although methodological approaches are centred within theoretical assumptions and beliefs about the social, it is important in ethically sound social science research for all contexts and influences to be acknowledged and evaluated (Christians, 2011). Thus, we argue that adopting a rights-based approach in health literacy research is essential if we are to uphold the principles set out in the UNCRC especially in relation to Article 12, the right to be listened to and have their views respected; the right to information – Article 17 and their right to guidance from adults – Article 5 (UNICEF, 2004). Future research directions in health literacy, we suggest, should additionally be based on the principles of a feminist ethic of care (Gilligan, 1982) in that they should actively embrace the moral activity of care, valuing children and young people as more than just recipients of care but also as participants within a social context, and engage in respectfully listening to participants’ views and experiences and in a feminist ethic of rights (Tronto, 1993). Feminist research has been applied extensively to explore health and illness, medical knowledge, the body, health and social movements, shifting the focus onto subject matters once considered private sphere issues, so the feminist ethics of care becomes crucial in challenging the complexity, diversity and contentiousness of research topics (Olesen, 2011).

If the research culture in the health literacy field is going to finally embrace children and young people, we suggest published research should evidence how it has valued meaningful relationships with participants to explore feelings and opinions and had engaged in a ‘rights-based discourse within the framework of an ethic of care’ (as outlined by Cockburn, 2005, p 73).

Previously overshadowed by scientific, positivistic approaches to research, Pleasant et al (2015, p 1177) argue that the field of health literacy reflects the
dominance of ‘other scientific endeavours that have strived to gain priority and credibility in society. However, that approach is insufficient to meet the needs of society, as well as being relatively useless to the healthcare professions.’ There is some resistance towards qualitative enquiry perceived of as lacking ‘scientific rigour’ (Erickson, 2011, p 55), and all too often research is subject to the ‘discourse of regulation’ (Hesse-Biber, 2014, p 99), thus the dominance of positivism and scientific approaches have influenced the control and direction of funders, research governance and ethics committees, and significantly undermined children’s rights to fully recognised as participants. However, unlike quantitative methods, qualitative methods incorporate a flexibility that enables researchers to be adaptable to the context of the research situation and to respond to the uniqueness of participant contributions (Silverman, 2006; Melia, 2010). A new toolkit for health literacy research with children and young people needs to be compiled that is based on respectful engagement: ‘Tapping into the child’s perspective is irrefutably valuable, in the sense that children’s own unique social worlds, experiences, opinions and understandings are acknowledged and respected, which can inform supportive healthcare practices and meaningful health promotion interventions’ (Velardo and Drummond, 2017, p 7). Therefore, rather than seeking data that validates theory, interpretivist research should be inductive and explore social phenomena through engagement and interactions to consider ‘if empirical material can encourage the challenging and rethinking of established theory and thus inspire novel lines of theory development’ (Alvesson and Kärreman, 2011, p 5).

Conclusion

There has recently been ‘a significant and steady expansion of health literacy research over the past decade’ (Cooper Bailey et al, 2015, p 1), which has included health literacy research in childhood and recognition that there is a need to focus on health literacy in younger children (Paakkari et al, 2016). However, much of this research has been focused on measuring health literacy (Pleasant et al, 2015), and it predominantly fails to include the views, experiences and perspectives of children and young people. While there is a limited, but admittedly growing, body of health literacy research related to children and young people, it is relatively very small when compared to the considerable interest accorded to that with adult populations (Bröder et al, 2017). The health literacy field needs to include more child-centred research approaches based on the principles of the UNCRC, adopt a more robust ethic of care towards children and young people and ensure that children and young people are viewed as knowledgeable about their lives (Mills, 2000; Back, 2009):

There needs to be shift in definition and measurement of health literacy from a healthcare orientation to an educational point of view, encompassing knowledge, skills, motivation, attitudes and a sense of
morality, and a shift in health literacy measurement from a simplistic, screening foundation to a more context specific, comprehensive nature. (Ormshaw et al, 2013, p 452)

Article 17 of the UNCRC states that children have the right to information that is important to their health and wellbeing (UNICEF, 2004). Future research endeavours to open up the research toolkit in health literacy in childhood needs to include ‘the potential benefits of emergent digital health technologies’ (Velardo and Drummond, 2017, p 9), and the role that mainstream social media can play in exploring and listening to children’s everyday experiences in the knowledge economy (Bond and Agnew, 2015). ‘The world is well into an era where technology is transforming how we conduct research, practice medicine, develop evidence-based public health interventions, and engage in our health and healthcare’ (Pleasant et al, 2015, p 1177), as such ‘we might consider how health literacy information seeking is influenced by the proliferation of media messages that convey sociocultural norms throughout the childhood years, or digitized, individualized “health promotion” technologies’ (Velardo and Drummond, 2017, p 7). Media health literacy is becoming an important concept for health promotion among young people (Zamir et al, 2011; see Chapter 18, this volume). Concerns have recently arisen that, although the proliferation of IT and access to the internet is potentially very positive in enabling people, including children and young people, access to health-related information online (Bickmore and Paasche-Orlow, 2012), it may simultaneously exacerbate existing inequalities and reinforce digital divides (Bond, 2014). The importance of critical digital literacy to help children navigate the wealth of information online is crucial to informing future research (Sonck et al, 2011) and also how children can develop resilience towards the unhelpful and potentially harmful ‘health’-related information online, especially in relation mental health and body image (Bond, 2018).

Borzekowski (2009) and Bröder et al (2017) conclude that health literacy can be empowering for children and young people who may be marginalised and potentially vulnerable:

Future efforts must target the redesigning of systems to be more inclusive and friendly towards children and young people, the adjustment of curricula and training of health professionals, teachers and other relevant stakeholders in order to better meet the challenge of the health literacy deficit, and the recognition of children and young people as active partners in their health decision making. (Bröder et al, 2017, p 23)

Previously children and young people’s views have not been valued in health literacy research, yet it is clear from other fields of enquiry that when they are given the opportunity to actively engage and participate in research, their voices can be heard and they can make powerful contributions to knowledge.
and understanding, policy and practice (Davey et al, 2010; Tisdall, 2013, 2015; Rawlings and Coombs, 2016). Furthermore, by drawing on a ‘multiplicity of voices’, media and opportunities to engage with social actors in more ethnographic ways, researchers can actively engage within postmodern contexts and reflexively construct meaning of and within the social realities (Delamont, 2003, pp 150-1). Issues around children and young people’s health and wellbeing are highlighted in policy discussions and research (DfE, 2015; DH, 2015; Law et al, 2015), yet there remains a significant lack of health literacy research engagement with children and young people themselves as to what they want, need or have found works for them (Couldry, 2010).

As Velardo and Drummond (2017) have argued previously, it is important that policy-makers understand the diversity of health literacy capabilities in different communities. The findings presented here emphasise the importance of undertaking health literacy research with children and evidences the very valuable contribution that children themselves can make to current understandings and future directions for health literacy research.

References


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