Developing an instrument for measuring the health literacy of adolescents: Lessons learned

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Measuring and improving the health literacy of adolescents: a lifespan perspective

From the perspective of lifespan developmental psychology, behaviour change processes occur from conception to death, as development is regarded as a life-long process, not assuming a special state of maturity. Childhood and adolescence are stages in which development and behaviour change are strongly influenced by biological maturation. Young people are undergoing cognitive, emotional, social and somatic change. Besides the influence of biological maturation on development, life events, for example, the death of family members, and history-graded influences, such as social change, also play a major role in influencing development. Hence, behaviour change does not necessarily persist into adulthood, as early life experiences are not presumed to prepare the individual for all situations of later life (Baltes et al, 1980). Still, health-related attitudes and health-promoting behaviour patterns are established and stabilised in childhood and adolescence, which can have a protective effect on later and more critical stages of the lifespan (Erhart et al, 2008; Voelcker-Rehage, 2012). Health literacy skills should therefore be enhanced in childhood and adolescence, as young people are increasingly managing their own healthcare, interacting with healthcare professionals and are exposed to health messages. Adolescents also have to manage developmental tasks and deal with health risks in their everyday life.

A commonly accepted definition determines adolescence as the lifespan ranging from 12 to 19 years of age. For health research, the cognitive development in this period is of particular interest, as it affects abilities connected with health literacy. During adolescence, cognitive development becomes apparent by the improvement of psychometric intelligence, logical thinking, autonomous regulation of decision-making processes and the processing of information (Silbereisen and Weichold, 2012). These cognitive abilities are of some importance, as they impact on the extent to which adolescents autonomously gain access, understand, appraise and apply health information. These abilities are defined as the core dimensions of health literacy (Sørensen et al, 2012).
Besides the cognitive development, Forrest et al (1997) conceptualised three further distinguishing characteristics that justify a separate focus in health research with young people: differential epidemiology, dependency and specific demographic patterns:

- Children and adolescents represent a relatively healthy population group. They are affected by a pattern of diseases that has a unique epidemiological profile.
- Parents play an important role for children and adolescents’ health education, health decision-making, disease management and entry into the health system.
- Country-specific demographic patterns must be considered, as adolescents might be affected by financial deprivation and social exclusion. Compared with adults and the elderly, children (aged 0-17 years) were the age group at the highest risk of poverty or social exclusion in Europe in 2015 (Eurostat, 2018).

Previous health literacy research has almost entirely addressed adults. Consequently, reliable data on the origin and characteristics of young people’s health literacy is lacking (Okan et al, 2015). Studies investigating the health literacy of children and adolescents have so far largely focused on specific health topics, such as nutrition (Ormshaw et al, 2013). Recently, more instruments measuring the generic health literacy of young people have been developed, varying widely by their underlying definitions and research purposes, considering different participant characteristics. However, a large part of these instruments use task performance-oriented measures (Okan et al, 2018, Guo et al, 2018). It is agreed that task performance-oriented methods neither adequately measure health literacy in different contexts and settings and nor do they capture the complexity of health literacy. Moreover, there is consensus that comprehensive validated measurement tools for diverse populations are required (Nutbeam, 2000; Wharf Higgins et al, 2009; Pleasant et al, 2011; see also Chapters 5 and 6, this volume).

For German-speaking countries, instruments measuring the generic health literacy of young people have either addressed 9- to 13-year-olds (Schmidt et al, 2010), 15-year-olds (Röthlin et al, 2013), young adults aged 18–25 (Abel et al, 2015), or specific populations, such as educationally alienated young people (Quenzel et al, 2015), or only assessed certain aspects, such as critical health literacy (Steckelberg et al, 2009) or health knowledge (Wallmann et al, 2011). Consequently, the development of an instrument measuring generic health literacy in adolescents in Germany appears to be necessary.

This chapter describes the process of developing and validating an instrument measuring generic health literacy in adolescents using qualitative methods as part of the project ‘MOHLAA – Measurement of Health Literacy Among Adolescents’. The next section focuses on the methodological approach, depicting methods and results of the qualitative approach. Results of empirical data are
analysed and discussed afterwards, followed by the conceptual framework of the MOHLAA questionnaire. The final section summarises implications for measurement instruments deriving from the empirical results, and the theoretical concepts of adolescent health literacy.

Development and validation of the MOHLAA questionnaire using a qualitative approach

The MOHLAA project was conducted at the Robert Koch Institute as part of the Health Literacy in Childhood and Adolescence (HLCA) Consortium, aimed at developing and validating an instrument for measuring generic health literacy in adolescents. The project encompassed two project stages – the development and validation of the first instrument draft using qualitative methods, and the quantitative validation of the finalised draft; the latter is not addressed in this chapter. The MOHLAA questionnaire (MOHLAA–Q) was developed for adolescents aged 14 to 17. As developmental stages differ greatly within the complete age range of adolescence from 12 to 19, the development of a single instrument adequate for all age groups might not be feasible. Hence, the instrument was designed for young people of mid-adolescence.

The development process of the MOHLAA-Q encompassed the design of a preliminary theoretical framework. Components of this framework were identified, based on theoretical concepts and expert knowledge, defined as a top-down strategy of instrument development (Bühner, 2011). Accordingly, the development process encompassed a literature review to identify the components of adolescent health literacy. Two focus groups with adolescents were conducted, as they can be viewed as lay experts concerning their experiences in navigating the healthcare system, managing diseases and staying healthy. A second strategy developing the instrument consisted of the use of the European Health Literacy Survey Questionnaire, German long version with 47 items (HLS-EU-Q47) (Sørensen et al, 2013), as a blueprint for the MOHLAA-Q.

The HLS-EU-Q47 encompasses the four dimensions of accessing, understanding, appraising and applying health information related to the domains of healthcare, disease prevention and health promotion. It was chosen as a blueprint, owing to its holistic approach, also covering the aspect of determinants of health in the social and physical environment. Developing the HLS-EU-Q47 in the European Consortium, adolescents did not participate in the validation process, except for the pre-test conducted in two countries. Due to feasibility reasons, the German survey was limited to the region of North Rhine-Westphalia (Sørensen et al, 2013). In an Austrian survey the applicability of the HLS-EU-Q16 short version has been proven adequate for 15-year-olds in a quantitative validation process (Röthlin et al, 2013). However, as the HLS-EU-Q47 was not pre-tested in Germany, and adolescents only participated in the validation process of other language versions, the applicability of the long version to adolescent age groups should be tested.
Cognitive interviewing of the HLS-EU-Q47 items

Cognitive interviews are particularly used in social sciences in order to conduct ‘qualitative pre-testing’ of items and to evaluate sources of response errors in questionnaires (Beatty, 2004). The technique of cognitive interviews is based on theoretical models of the question–answering process. The most general model was developed by Tourangeau (1984), conceptualising four processes: comprehension of the question, retrieval of relevant information from memory, estimation process and response process (Willis, 2015).

Using a snowballing technique, a purposive sample of 20 adolescents aged 14–17 was drawn, a sample size assumed adequate for cognitive interviews (Prüfer and Rexroth, 2005). Interviews were conducted between December 2015 and March 2016, lasting approximately 55 to 110 minutes. Adolescents were quoted in terms of gender, age and levels of secondary education. Two trained interviewers conducted the interviews, using a semi-structured interview guide. Interviews were recorded and partially transcribed. Fifteen out of 47 items of the HLS-EU-Q47 were selected for testing, based on results of a pre-test of one HLS-EU-Q subscale (Jordan et al, 2014) and on the results of the Austrian survey, indicating difficult items (Röthlin et al, 2013). The questionnaire provides a four-point scale (very easy, easy, rather difficult, very difficult): ‘On a scale from “very easy” to “very difficult”, how easy would you say it is to….’

The cognitive interviewing techniques of ‘verbal probing’ and ‘retrospective think-aloud’ were used in order to investigate whether items were understood in the intended way, and whether adolescents had experience with the described health-related situations in different settings.

Transcripts, interview protocols and notes on observation were analysed, based on a cognitive model of the survey response process (Tourangeau, 1984). The framework approach was applied, a method used in health research to facilitate the categorisation of qualitative data (Gale et al, 2013). A small part of the data was independently categorised and coded by two researchers in order to satisfy criteria of reliability.

Data analysis revealed three dominant themes:

• comprehensibility of items
• motifs of choosing a response option
• experiences with specific health-related situations.

These themes will be exemplified by crucial interview statements from adolescents; for more examples, compare Domanska et al (2018).

Comprehensibility of items

Not all items of the HLS-EU-Q47 were well understood by the adolescents. The following two examples illustrate this. Adolescents were asked to rate their
Motifs of choosing a response option

In case an item or term was not well understood, some adolescents chose the response option ‘very difficult’. For example, in terms of item 11 (see above), one adolescent stated that he did not understand the term ‘second opinion’ but chose the response option ‘very difficult’ instead of not responding. This appears to indicate that the response reflects the difficulty of understanding the item rather than the difficulty of the assessed competence. Despite not knowing specific terms used in the questions or not understanding the issues covered by the items, some adolescents chose a response option rather than not responding. As only a few missing data could be observed, these results suggest biased data.

Experiences with specific health-related situations

Adolescents have no experiences with some of the described health-related situations in different settings. The following two examples illustrate this. Adolescents were asked to rate their competencies: ‘how easy would you say it is to…’ with item 6, ‘understand the leaflets that come with your medicine?’ One adolescent stated that he did not read the leaflets that came with the medicine, but was of the opinion that he would understand them if he did read them. Accordingly, he chose the response option ‘easy’. For item 47, ‘take part in activities that improve health and wellbeing in your community?’, most adolescents had difficulty understanding this, because they could not imagine how an activity could have an impact on an individual’s health and wellbeing. They also chose the response option ‘easy’. These results suggest that adolescents who lack experiences with health-related situations in different settings overestimate their health literacy.

Focus groups

Focus groups represent a qualitative, explorative method, also deemed appropriate to investigate people’s experiences of managing diseases and navigating health
services (Kitzinger, 1995). This method has also been used with young people in health research and can specifically be used to generate items for inclusion in questionnaires (Detmar et al, 2006).

A purposive sample of 12 adolescents aged 14 to 17 was drawn, quoted in terms of gender, age and education level. Two focus groups were carried out in January and February 2016, lasting approximately 60 minutes. One was conducted with adolescents aged 14 to 15 \( (n=5) \), the other with adolescents aged 16 to 17 \( (n=7) \). Focus group discussions were conducted and analysed by the first author, partially protocollled by a student assistant and audio taped. The guided focus groups investigated adolescents’ knowledge and experiences regarding healthcare, disease prevention and health promotion, corresponding to the domains of the HLS-EU-Q. As vignettes have proven to be a feasible method to obtain data in mental health literacy research (Leighton, 2010; Olsson and Kennedy, 2010), three vignettes were included in the discussion guide, focusing on the following scenarios: bullying at school; hepatitis B vaccination/piercing; attention deficit hyperactivity disorder/decision-making. The third vignette is presented here as an example:

Paul suffers from hyperactivity. He went to see a doctor with his parents and has taken Ritalin for three months. Paul wants to stop taking the pills because he doesn’t like how it feels. He doesn’t like playing the drums any more. His parents would like him to continue taking the pills so that he is able to better concentrate in school. What would you advise him to do?

Data was analysed with the method content analysis (Mayring, 2015) using the data analysis software MAXQDA 12. Analysis and categorisation of the focus group data revealed the issues of:

• adolescents’ experiences navigating the healthcare system or managing diseases;
• parents providing health information and advice;
• health decision-making in the family context;
• comprehending complex issues and joining the dots.

**Adolescents’ experiences navigating the healthcare system or managing diseases**

Focus group participants stated that they did not often visit a doctor. One adolescent reported not having a family doctor: “I do not have a doctor – at the moment…. But I do not get ill…. I had a sore throat once during the last two years”. Furthermore, adolescents were invited to discuss the third vignette (see above), and were asked to give advice on how to deal with the presented dilemma. Several adolescents indicated this as the most difficult question of the
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focus groups, as they had no experience with the regular intake of medication, and thus no experience with such dilemmas.

**Parents providing health information and advice**

Adolescents reported that the first source of health information was (in most cases) their parents. Adolescents turned to them for information about health and for advice. They stated seeking advice from them in case of unknown signs of illness, decisions about medication or the necessity of seeing a physician. Depending on the health topic, they also named other sources of information: friends, teachers and healthcare professionals.

**Health decision-making in the family context**

Adolescents were asked how they knew that their parents’ advice concerning health decisions was correct. One adolescent responded spontaneously: “Eltern wissen alles” [“Parents know everything”]. Another adolescent reported that he had been vaccinated before going on holiday. He stated that he did not know against which disease, and that he had simply acted on his parents’ advice. Furthermore, some adolescents explained that certain health decisions, for example, changing to a vegetarian diet, required discussion and agreement with family members – they stated that they would need to explain this decision to their family. Some believed that their parents would not agree to such a change.

**Comprehending complex issues and joining the dots**

In terms of health promotion and the determinants of health – staying healthy – adolescents reported that they had difficulty imagining how they could influence their living conditions in such a way as to improve their health. It appeared to be a challenge for them to join the dots between living conditions and their health status. Discussing media use, adolescents stated using the internet frequently. However, it became evident that they were not aware of criteria they might need for appraising the reliability of web pages. Adolescents believed that they would easily find reliable information on the internet, and consequently overestimated their media competencies.

**Analysis and discussion of empirical results**

The results of the cognitive interviews and focus groups reveal different issues relevant for the development of questionnaires aiming to measure the health literacy of adolescents. One issue area addresses the comprehensibility of questions and the stability of responses, while a second focuses on the relevance of interaction for adolescent health literacy.
Comprehensibility of questions and stability of responses

The comprehensibility of survey questions for children and adolescents has been investigated in the area of childhood studies and survey research. Results indicate that the higher the cognitive abilities of the children, the less problems with an adequate response (Emde and Fuchs, 2012). Moreover, the type and difficulty of a question influences data quality, since questions related to attitudes, behaviour or estimation demand higher levels of abstraction than questions related to facts. As the difficulty of a question appears to be a crucial factor for data quality, rules for the development of clearly understandable questions and answers in questionnaires (compare, for example, Payne, 1951; Krosnick, 1999; Faulbaum et al, 2009) are even more important for young people's measurement instruments. Owing to their further developed cognitive abilities, self-reports of adolescents are regarded as more stable compared with self-reports of children (Reynolds, 1993). Although the study by Borgers et al (2000) indicates that adolescents aged 15 and over can be treated as adults in surveys, the results of the MOHLAA study contradict this statement. Findings suggest that adolescents seem not to be aware of the complexity of issues and the demands of specific health-related situations. This observation can be interpreted in two ways: adolescents either lack knowledge about complex issues, for example, the knowledge necessary to understand the impact of laws on health; or their cognitive abilities are not fully developed, so that these items are still too complex to be understood. To summarise, data quality in surveys of young people is affected by adolescents' knowledge and cognitive abilities and the difficulty of items. Difficult items, requiring well-marked abilities of abstraction and comprehension of complex issues, might, in the best case, cause missing values or alternatively biased data.

The stability of children and adolescents' responses has been investigated in survey research. In case the context of a survey question refers to personal experiences and the living environment of children and adolescents, there are far fewer biases than in abstract knowledge domains (Lipski, 2000; Diersch and Walther, 2010). Since adolescents represent a relatively healthy population, they have limited experience with navigating the healthcare system or managing diseases. According to the results of the MOHLAA study, adolescents respond to questions despite not having the relevant experience, with some of them overestimating their competencies. Biases in young people's surveys might thus be founded in a lack of experiences with specific health-related situations.

The assumption that some adolescents overestimate their health literacy might be grounded in their competence-oriented self-concept. During adolescence, the ability of young people to describe their performance enhances and comparisons with others gains in importance. Adolescents learn to describe their performance in situation-specific contexts (Filipp and Mayer, 2005). Studies investigating self-concepts demonstrate that results often tend to the positive pole. Information relevant for self-esteem is often not objectively processed but rather motivated
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by the acquisition of a stable, positive self-concept (Dauenheimer et al, 2002), representing a self-serving bias.

In summary, the lack of experiences with specific health-related situations and the lack of knowledge about complex issues, such as, for example, health policy, has an impact on the comprehensibility of a survey question and might cause biased data. Adolescents’ possible overestimation of health literacy might, on the one hand, be grounded in this lack of experiences or knowledge and, on the other, in the need for a positive self-representation.

Relevance of interaction for adolescent health literacy

Studies on the health information seeking of adolescents demonstrate that parents are the most important sources of information (Ackard and Neumark-Sztainer, 2001; Baheiraei et al, 2014). Moreover, parents and significant others are defined as interpersonal socialisation agents. Adolescents’ health literacy is strongly connected with the amount of health information provided, and should be understood as a complex interplay among interpersonal and media socialisation agents and multiple factors (Paek et al, 2011).

However, findings of the MOHLAA study indicate that adolescents not only seek information from their parents; they also seek advice in order to make health decisions and to get support in terms of the management of diseases. Adolescents also state that they trust their parents concerning these issues. Some stated that in the case of using a health measure (for example, a vaccination), they simply acted on their parents’ advice, because they trust them. These findings are in line with the results of a qualitative study investigating health decision-making in young people with a disability or who are chronically ill (Mitchell, 2014). Mitchell emphasises that adolescents need communication and emotional support from their parents before they arrive at a health decision. Young people stated that they value their parents’ opinions and knowledge, and trust them to understand their feelings. Apparently, the described interactions between adolescents and parents seem to be characterised by a certain relationship quality. As adolescents state they trust their parents, this quality might be characterised as connectedness, defined by Beyers et al (2003) as the property of a relationship system encompassing the dimensions of ‘mutual reciprocity, trust and dependency’ (2003, p 360). As such it is regarded as a protective factor for adolescent health (Sieving et al, 2017).

At the same time, results of the MOHLAA focus group indicate the dependency of adolescents on their parents in terms of decision-making and behaviour change. In case the adolescents’ decisions are not supported by their parents, behaviour change might not be realised, regardless of whether the decision reflects high or low health literacy. To summarise, interaction with family and significant others is crucial for adolescents’ abilities to evaluate information in order to make sound health decisions and to manage diseases. However, as adolescents represent a relatively healthy population group, most of them do not have experiences with health decisions in terms of significant medical interventions. Furthermore, the
quality of the child–parent relationship shapes this interaction and can have a protective effect on adolescent health.

Limitations

Analysis of qualitative data was limited due to the sample sizes of both focus groups and cognitive interviews. As they were not provided for in the study design, only two focus groups were conducted. Consequently, an achievement of redundancy in information or theoretical saturation of data cannot be claimed (Bowling, 2014). The sample size of 20 cognitive interviews is assumed adequate to satisfactory obtain information on the research questions, but was insufficient for sub-group analysis by educational level, age and gender. Furthermore, migrant background was not considered as a sample characteristic, though language proficiency or bilingualism might have affected the understanding of the questionnaire (Jacobson et al, 2016). Composition of focus groups only considered similar age-ranges, though health topics like sexual health would have required same-sex groups to facilitate free discussions on a gender-sensitive issue. Qualitative data should be categorised and coded by two researchers to discuss discrepancies and agree on final categorisation (Bowling, 2014). This procedure was only carried out for small parts of the data, due to its very time-consuming nature.

Framework concept of the MOHLAA questionnaire

Constructs of children and adolescents’ health literacy are highly diverse, with 20 different models depicting the health literacy of young people. Children and adolescents’ health literacy is mostly defined as a multidimensional construct with a focus on the acquisition of individual competencies and knowledge (see Chapter 3, this volume). Definitions of health literacy also acknowledge the interdependency of health literacy with social context (Sentell et al, 2017). The systematic literature review by Bröder et al (2017) has identified the diverse models of health literacy and categorised the components according to cognitive, behavioural or operational, and affective and conative competencies. The conceptual framework of the MOHLAA-Q is based on this categorisation, and thus comprises behavioural and operational components, covering, for example, the dimensions of finding or evaluating health-related information, affective and conative components, covering, for example, health consciousness and health motivation. The instrument is complemented by an objective measure, assessing health knowledge. This objective measure facilitates investigating how adolescents’ self-reported competencies and their health knowledge correspond. Finally, adolescents’ perceived conditions to act in a health-literate way are assessed in order to consider the interrelatedness with contextual factors. This component covers, for example, how adolescents perceive health-related communication with physicians or family.
Implications for the development of instruments measuring adolescent health literacy

Data quality in surveys of young people is affected by adolescents’ knowledge and cognitive abilities and the difficulty of items. Instruments measuring the health literacy of adolescents should therefore be adapted to adolescents’ development-dependent knowledge and state of cognitive development to ensure the comprehensibility of questions and response options in questionnaires. Complex items that require higher levels of abstraction need to be adapted. This may involve the adaptation of wording, the addition of concrete examples or the reduction of the complexity of the issues covered by the items. Furthermore, questions should refer to personal experiences and the living environment of children and adolescents, considering their limited knowledge and experiences with health-related situations in different settings. In addition, since the findings of the MOHLAA study suggest that parents and significant others play an important part in adolescents’ health decision-making and the management of diseases, instruments should incorporate this interaction. To summarise, results suggest that the use of qualitative methods is necessary to verify the practicability of an instrument for adolescent age groups.

As the results also suggest that some adolescents’ overestimate their subjective health literacy competencies, representing a phenomenon of subjective measurement, assessment approaches should be complemented by objective measurement tools. Provided that these mixed methods are based on coherent underlying constructs, the correlation of adolescents’ self-reported and objective competencies could be investigated (Altin et al, 2014). Finally, since health literacy is interrelated with social and contextual determinants, instruments measuring adolescent health literacy should aim to capture contextual factors. Depending on the perspectives of the intersection between health literacy and social context, approaches may focus on the individual level or measure social context as independent property (Sentell et al, 2017).

Owing to adolescents’ developmental abilities, dependency on adults and differential epidemiology, a separate focus on health research is highly recommended to prevent biased data in adolescents’ surveys. Sound empirical data on the characteristics of adolescents’ health literacy is required in order to tailor measures to their specific needs. Promoting health literacy effectively at an early age might contribute to the enhancement of present and future health behaviour and the health status of young people.

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References


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