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Measuring children's health literacy: Current approaches and challenges

Torsten Michael Bollweg and Orkan Okan

Introduction

Starting at an early age, children are confronted with a plethora of health information in their everyday lives. This information might be communicated by their parents regarding healthy food, physical activity, preventing illness or general health risks. It may also be taught in school, provided by various media channels or discussed with friends and peers. While there is evidence that a vast proportion of the adult population have difficulty understanding or effectively using health-related information (Sørensen et al, 2015), there is barely any research on questions such as:

- How difficult is it for children to access health information?
- Can children understand what they learn about health?
- To what extent do children critically appraise health-related information?
- What opportunities do children have to apply health information in their daily lives?

Health literacy and appropriate tools for its measurement can provide answers to questions like these. However, for the last few decades, research on health literacy has paid little attention to younger age groups, and children younger than 13 years of age in particular (Ormshaw et al, 2013; Okan et al, 2018). For adult populations, various health literacy models, definitions and approaches have emerged over the years (Sørensen et al, 2012; see also Chapter 1, this volume). Simultaneously, a wide range of measures have been developed and used in different contexts (Haun et al, 2014), some of which have been criticised for not being based on existing models or definitions (Pleasant, 2014). For more information, see Chapter 5, this volume.

A multitude of studies has documented the adverse effects of limited health literacy on health-related outcomes. For example, a low level of functional health literacy (see Chapter 14, this volume) has been linked with an increased risk of hospitalisation, worse medication knowledge and skills, and a higher risk of misunderstanding medication and food labels (Berkman et al, 2011). Thus,

health literacy is recognised as a critical determinant of health, and an important driver of empowerment and equity that should be promoted starting in school age (WHO, 2017). While the potential to foster health literacy through school health education was already considered more than 40 years ago (Simonds, 1974, p 9), it has been neglected until recently (Ormshaw et al, 2013; see also Chapters 2 and 34, this volume). Nowadays, there is growing consensus that the early promotion of health literacy could be foundational for good health literacy and positive health outcomes later in later life (Manganello, 2008, p 840; WHO, 2017). However, there is hardly any evidence on children's health literacy to inform innovations in health education curricula, interventions or health literacy programmes. Still, a solid evidence base is imperative to address these issues and to sustainably promote the health literacy of coming generations.

The lack of evidence is directly related to the scarcity of measurement tools, which can be observed for younger populations in general, but even more so for children. Although two systematic reviews have identified a total of 25 health literacy tools for children and adolescents (Ormshaw et al, 2013; Okan et al, 2018), the majority of these were developed for adolescents rather than for younger children. Therefore, little is known about the proportion of children with limited health literacy, or about how children interpret and use health information in their everyday lives. Accordingly, a targeted and evidence-based approach to the promotion of children's health literacy is inhibited by a lack of evidence. Thus, the development of child-specific measures is needed, as well as the implementation of high-quality surveys that assess the various components of health literacy.

This chapter aims to provide an overview of current approaches towards the measurement of health literacy in populations younger than 13 years of age, as well as a discussion of challenges and potentials in this field of research. While the selection of an age limit to distinguish children from adolescents can be somewhat arbitrary, a maximum age of 12 was chosen to exclude teenagers, and to bring into focus younger age groups.

Available tools and challenges

As reported earlier, only two systematic literature reviews have analysed health literacy tools for children and adolescents. Ormshaw and colleagues (2013) reviewed the literature until 2011 and found 16 tools, including measures of generic health literacy as well as mental and media health literacy. Okan and colleagues (2018) included only measures of generic health literacy instruments, and identified 15 different tools. Together, the reviews report on a total of 13 instruments that have been used to measure *children's* health literacy, that is, of participants younger than 13. In the following, findings of both reviews have been compiled to provide a broad, systematic overview of these measures. Particular attention is drawn to: target groups; health topics; components of health literacy; measurement design; and methodological rigour.

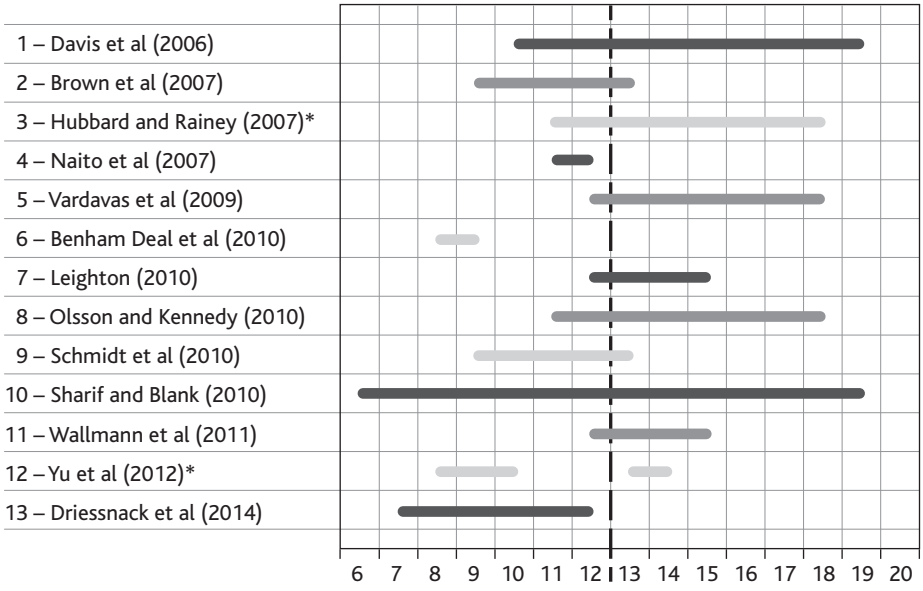
Target groups

Examining the age groups (see Figure 6.1), it becomes apparent that the number of studies primarily targeting children is limited, with only six tools found (Brown et al, 2007; Naito et al, 2007; Schmidt et al, 2010; Yu et al, 2012; Benham Deal et al, 2013; Driessnack et al, 2014). Another seven studies report on instruments that have been used primarily among adolescents or adults, but also include children (Davis et al, 2006; Hubbard and Rainey, 2007; Vardavas et al, 2009; Leighton, 2010; Olsson and Kennedy, 2010; Sharif and Blank, 2010; Wallmann et al, 2012).

Remarkably, the youngest age groups (6-7) were included in two studies that used adult instruments (nos 1 and 10; see Figure 6.1). Also, vast differences are visible with respect to the age range: while Benham Deal and colleagues (2013) and Naito and colleagues (2007) focused on samples with an age range of just one year (8-9 and 11-12), ranges of up to 9 or even 13 years can be found in the studies conducted by Davis and colleagues (2006) and Sharif and Blank (2010), respectively.

Of 13 instruments, 10 were newly developed for the purpose of the study. Two of the instruments, namely, the Newest Vital Sign (NVS, no 13) and the Short Test of Functional Health Literacy in Adults (S-TOFHLA, no 10) were originally developed for adults and were validated for use in younger populations without making any age-related adjustments to the instruments. In contrast, one

Figure 6.1: Age of participants in the studies



Notes: Sorted by year of publication, then alphabetical order.
* Age not reported in article: estimated based on grade levels.

study sought to validate an age-adapted version of the Rapid Estimate of Adult Literacy in Medicine, namely, the REALM-Teen (no 1).

In their review, Okan and colleagues (2018) also assessed whether children participated in the development of the respective instruments, and found that this was the case in only two studies. In these studies, qualitative interviews were conducted to verify the comprehension of questionnaire items (nos 2 and 3). Apart from that, they have not identified studies that implemented further child participation. While Ormshaw and colleagues (2013) did not investigate target group participation, brief screening of the articles shows that only one study applied pilot testing with the respective age group (no 7).

Challenges

First, it can be stated that 'the paradox of the missing child' (Darbyshire et al, 2016) is prevalent in this field of research. While all of the authors aimed to conduct research *on* children, most of the authors neither included children for feedback nor aimed to learn about their perspectives and experience (research *with* children). For future research, child participation is desirable and necessary to ensure the quality of measures and to enhance researchers' learning on children's health literacy.

Second, while the majority of measures have been developed for younger populations, measures were identified, too, that have been developed for adults (nos 10 and 13). The use of adult instruments among children has to be questioned, even when the respective measures have previously proven to be reliable and valid. For example, Sharif and Blank state that the S-TOFHLA is 'feasible for use in children' (2010, p 46), but also express 'uncertainty' regarding the use of their tool in order to measure children's health literacy (2010, p 46). Similarly, the NVS is described as 'a feasible, useful, and valid tool for children as young as 7 years of age' (Driessnack et al, 2014, p 169), but Warsh and colleagues (2014, p 143) recommend the use of the NVS with children no younger than 10. Hence, thorough discussion and replication of results is commanded when developing tools, even more so when adult measures are applied. Furthermore, the development of age-specific tools is advised, in contrast to the re-utilisation of measures for adults.

Health topics

Health literacy is contextual (Nutbeam, 2000). Thus, the ability of an individual to use health information effectively depends on situational demands, and the respective area of health. While some instruments apply a narrow focus on just one health topic (nos 1, 2, 4, 7, 8, 10 and 13), a broad range of health domains are addressed in other instruments (nos 3, 5, 6, 9, 11 and 12). It can be observed that instruments addressing health literacy in healthcare contexts (nos 1, 10 and 13) tend to focus on one single aspect and not include other health domains, which

also applies to instruments focusing on mental health (nos 7 and 8). In contrast, there are also instruments that focus on up to seven health topics (nos 9, 11 and 12).

Challenges

The research streams on functional health literacy in medicine (nos 1, 10 and 13), as well as on mental health literacy (nos 7 and 8), are fairly distinct – methodologically and regarding content – from more comprehensive approaches. Thus, researchers are faced with a choice between measures of generic health literacy, which simultaneously assess multiple health topics, and domain-specific measures, which focus on a single health topic.

One the one hand, there is merit in measuring health literacy with respect to a single health topic. A child's level of health literacy with regard to oral health might not be comparable to that child's health literacy with respect to mental health. To that end, the application of specialised measures seems appropriate, and more practical with respect to informing specific interventions. However, findings from such specialised studies ought to be communicated and discussed very cautiously. For example, the 13 identified studies do not provide evidence on the general health literacy of children, but rather, fragmented information on children's health literacy regarding a variety of specific health topics. Hence, the emergence of different terminological concepts, such as media health literacy, mental health literacy, and so on, seems consequential.

On the other hand, measures of *generic* health literacy seek to assess the overall level of health literacy across multiple health topics and contexts. Such general measures can be useful, for example, to provide data on the efficacy of school health education, or on the ability of a population to use health information effectively, regardless of health topics. The aim of measuring health literacy comprehensively, however, translates to a broader scope of measurement, which is why measures of generic health literacy could prove impractical for the quick screening of patients.

Eventually, there is growing consensus 'that health literacy is too broadly defined to realistically allow a single, all-encompassing measure that could be used by researchers and clinicians alike' (van der Ploeg, 2010, p 145), which is why there is a need for both specific and general tools.

Components of health literacy

While some recurring themes in the measurement of children's health literacy can be identified, there are hardly any overlaps between the different operationalisations (see Table 6.1). For example, health-related theoretical knowledge is measured by five measures (nos 3, 6, 9, 11 and 12), and understanding of health information (nos 2, 3 and 5), as well as attitudes (nos 2, 9 and 12) are each assessed by three approaches. However, each other component is assessed by a maximum of two measures.

Table 6.1: Measures of children's health literacy

#	Authors	Measure	Design	Health topics	Components of health literacy	Age
1	Davis et al (2006)	REALM-Teen	p	Medicine	Word recognition, pronunciation	10-19
2	Brown et al (2007)	Kids-Health KidsPoll	s	General health	Understand, access, apply health information, interest, belief, attitude	9-13
3	Hubbard and Rainey (2007)	HEAP items[a]	p	Physical activity, nutrition/diet, smoking	(Theoretical) knowledge, understand, access health information, communication, self-management	11-18+
4	Naito et al (2007)	Questionnaire	p	Oral health	Critical thinking/ evaluation	11-12
5	Vardavas et al (2009)	Questionnaire	s	Oral health, STDs, physical activity, smoking, nutrition	Access to and sources of health information, satisfaction with health-related interactions	12-18
6	Benham Deal et al (2010)	HEAP items	p	Personal safety and injury prevention	(Theoretical) knowledge, service navigation	8-9
7	Leighton (2010)	Vignettes	p	Mental health	Recognition, practical knowledge (treatment options)	12-15
8	Olsson and Kennedy (2010)	Vignettes	p/s	Mental health	Recognition, practical knowledge (treatment options), help-seeking behaviour	11-17+
9	Schmidt et al (2010)	GeKoKids questionnaire	p/s	Physical activity, nutrition, smoking, vaccination, oral health, general health	(Theoretical) knowledge, attitudes, communication, self-efficacy, behaviour	9-13
10	Sharif and Blank (2010)	S-TOFHLA	p	Medicine	Reading comprehension	6-19
11	Wallmann et al (2011)[b]	Health quiz	p	Nutrition, smoking, body weight, blood pressure, media use, physical activity, human body	(Theoretical) knowledge	12-15

(continued)

Table 6.1: Measures of children's health literacy (continued)

#	Authors	Measure	Design	Health topics	Components of health literacy	Age
12	Yu et al (2012)	Health Literacy Questionnaire	p	Nutrition, disease prevention, substance abuse, injury prevention, physical activity, growth and development	(Theoretical) knowledge, attitude, behaviour (health practice)	8-10, 13-14
13	Driessnack et al (2013)	NVS	p	Nutrition	Reading comprehension, numeracy	7-11

Notes: p = performance-based test; s = self-report measure; [a] Items from the proprietary Health Education Assessment Project (HEAP) database; [b] Study published in German only.

Source: Based on literature reviews conducted by Ormshaw et al (2013) and Okan et al (2018)

Although health literacy is increasingly being regarded as relational and context-specific (Sørensen et al, 2012), the contextuality of health literacy is barely recognised by the different instruments. For example, Okan and colleagues (2018) found that only two measures of children's health literacy take into account contextual factors or situational determinants (nos 6 and 10).

Challenges

First, there is neither an agreed upon theory of health literacy, nor are there commonly accepted models or definitions for children and adolescents' health literacy. Instead, there are a number of conflicting as well as complementing models and concepts that express specific understandings of what are the constituent elements of health literacy, its antecedents and its outcomes (Bröder et al, 2017). Both reviews find that not all studies are built on definitions of health literacy. This further exacerbates the lack of comparability, and the question can be raised 'if the available instruments are actually measures of the same construct' (Baker, 2006, p 878). It can be stated that measures of functional (nos 1, 10 and 13) and mental health literacy (nos 7 and 8) do indeed not measure the same construct or components of health literacy, also when compared to the other measures. For future research, it will be increasingly necessary to state the underlying definition of health literacy and to clarify which of the components of the definition are measured, and how they are operationalised. The latter is especially relevant, as a number of studies use the definition of health literacy by Nutbeam (2000) as a general framework, but chose vastly different approaches to measure children's health literacy (for example, nos 5, 9 and 11).

Second, the question can be raised to what extent the identified measures actually assess health literacy. In particular, it is disputed that measures of functional

health literacy are appropriate measures of today's broad understanding of health literacy (Ormshaw et al, 2013, p 435). However, it has to be acknowledged that these measures were never intended to measure general, comprehensive health literacy (Baker et al, 1999; Weiss et al, 2005, p 521; Davis et al, 2006, p 1710). Thus, it needs to be understood that measures of functional health literacy are as different from comprehensive measures as are measures of mental or digital health literacy. Additionally, functional health literacy has been criticised due to its proximity to basic cognitive abilities that are not health-specific (Reeve and Basalik, 2014). It is probable that other dimensions of health literacy, such as the ability to access, understand or appraise health information, will be scrutinised in a similar manner. It remains a challenge to define what is genuinely health-specific about these components of health literacy.

Third, there have been calls for a significant advancement of the scope of measurement of (children's) health literacy. Among the possible advancements are, for instance, 'language, context, culture, communication, or technology' (Mancuso, 2009, p 87), or the 'ever-present or underlying stress or fear factor' inherent in health contexts (Institute of Medicine, 2004, p 41). Additionally, health literacy is increasingly being regarded as two-sided, relational or contextual. For example, adequate health literacy might not be determined by a static level of knowledge, or the proficiency of using health information, but rather, by the relationship of the knowledge and skills a child *has*, and the knowledge and skills a child *needs* to cope with health-related challenges. The other side of the 'health literacy equation' is increasingly being investigated, for example, through approaches on the *health literacy responsiveness* of health services (Trezona et al, 2017), or the related concept of *health-literate organisations* (Brach, 2017). Approaches like these contribute significantly to the advancement of health literacy research, as they shift the focus on health literacy away from individual skills and responsibility, towards the system level contexts of health literacy. However, further advancements are necessary, which might include measures that also assess 'the health literacy demands on individuals within different health contexts' (Institute of Medicine, 2004, p 51). Thus, future measures of children's health literacy are faced with ever-increased demands in terms of complexity.

Measurement design

A range of approaches for measuring children's health literacy can be identified. While almost all of the measures applied a questionnaire-based approach, only two instruments were administered as face-to-face interviews (nos 1 and 13). Notably, both measures of mental health literacy (nos 7 and 8) apply case vignettes, which are a common tool in the field of mental health literacy (Leighton, 2010, p 232). Five instruments apply a combination of closed-ended and open-ended items (nos 4, 6, 7, 8 and 12), and another five use closed-ended items only (nos 2, 5, 9, 11 and 12). Two instruments are conducted as interviews, in which no choice of possible answers is provided (nos 1 and 13), and one study does not report on

the response format (no 3). Nine measures apply performance tests (nos 1, 3, 4, 6, 7, 9, 10, 12 and 13), three instruments apply self-report only (nos 2, 5 and 12), and one instrument applies both (no 8).

Challenges

First, it is difficult to make generalised recommendations about how health literacy should be measured, as the appropriateness of measurement designs depends on the measured component of health literacy. While it seems obvious that health-related knowledge is best measured by a performance test, it is not entirely clear how health-related skills should and could be measured. While performance tests to assess children's ability to access, understand, appraise and apply health information would certainly be the most valid approach, such tests are yet to be developed. Furthermore, approaches towards the measurement of the perceived difficulty of accessing, understanding, appraising and applying health information (*subjective* health literacy; see Sørensen et al, 2012) could be fruitful to assess children's health literacy as a truly relational concept, that is, as the relationship between perceived skills and health-related challenges. Currently, it seems plausible that 'objective' (knowledge and skills) and 'subjective' health literacy could independently provide insights into different aspects of health literacy. Eventually, further research is necessary to investigate the efficacy of the different approaches and their potential to predict health-related outcomes.

Second, no qualitative approaches on measuring children's health literacy have been identified by the reviews. However, interviews, focus groups or field research into children's health practices could contribute significantly to researchers' understanding of children's health literacy. The work by Fairbrother et al (2016) can be named as an example for research 'beyond *what* children know' towards research on '*how* children actively construct meaning from health information' (2016, p 476). Future research will need to adopt such perspectives to improve the measurement of children's health literacy, but also to accelerate the development of a definition of children's health literacy.

Methodological rigour

While all identified studies contribute to the knowledge base on children's health literacy, differences can be observed regarding the quality of evidence. Ormshaw and colleagues (2013, p 451) conclude that 'each of the studies followed sound research methods and principles', but also note that 'it is hard to assess the reliability … of the studies.' Regarding sampling procedure and sample size, for example, a convenience sample with 47 parent–child dyads (no 13) and a multi-stage cluster-stratified sampling survey with 8,008 participates (no 12) mark the end points of a spectrum.

Cronbach's α is the most frequently reported indicator of internal consistence/reliability (nos 1, 3, 9, 12 and 13), and two studies use additional indicators of

reliability, namely, re-test reliability (no 1) and split-half reliability (no 12). Eight studies report no indicator of reliability (nos 2, 4 to 8, 10 and 11). Both studies that use HEAP items refer to them as having previously been tested for reliability (nos 3 and 6). Indicators of validity are reported in five studies, whereby two studies rely on face validity, as established by experts (nos 2 and 6). Concurrent validity is reported for two instruments (nos 1 and 13), and one instrument seeks to establish validity by developing the instrument based on the literature, receiving expert feedback and piloting the measure (no 7). Five studies report neither indicators of validity nor reliability (nos 4, 5, 8, 10 and 11).

Challenges

First, the small number of studies reporting on indicators of validity and reliability highlights the need for more transparent reporting and methodological rigour. However, there is also potential for improvement where such indicators are reported. For example, face validity cannot be verified where items are not reported. Also, due to the scarcity of measures of children's health literacy, concurrent validity cannot be established in many cases until similar measures are available. Additionally, future research should acknowledge that Cronbach's α can be inflated by a high number of items, and thus it is not necessarily a good indicator of the unidimensionality of a scale (Streiner, 2003, pp 101-2), although more costly, repeated testing and the assessment of re-test reliability might be helpful to investigate the reliability of future measures. Furthermore, even more thorough testing and reporting can be expected from those measures that are designed to inform professionals in clinical settings (REALM, TOFHLA and NVS). However, indicators of sensitivity and specificity have only been reported for the NVS (Driessnack et al, 2014, p 167).

Second, future research should aim to test measures of children's health literacy in representative samples to allow for an estimate of psychometric properties in the general population or a specific subgroup. The use of small convenience samples might be useful for the initial stages of instrument development, but inferences about the feasibility and quality of a measure may be limited.

Latest developments

Ormshaw et al (2013) and Okan et al (2018) have provided a systematic overview of available measurement tools for children and adolescents. However, the reviews are limited to studies published until April 2011 and July 2015, respectively. Therefore, in this section, some of the latest developments are briefly presented:

- Mulvaney et al (2013) adapted the Diabetes Numeracy Test (DNT) for type 1 diabetes among adolescents aged 12-17. Versions with 14 (DNT-14) and 39 performance test items (DNT-39) are available that have been used to assess

numeracy with respect to the self-management of diabetes in a sample of 133 participants.

- The Health Literacy Assessment Scale for Adolescents (HAS-A) aged 12-19 has been developed by Manganello et al (2015). HAS-A is a 15-item self-report measure that was used to assess health literacy in the areas 'oral communication' (5 items), 'confusion' about health information (4 items) and 'functional health literacy' (6 items) among 272 adolescents.
- The Taiwan Children's Health Literacy Test (TCHL) was developed by Liu et al (2014) for children aged 11-12. In a survey among 162,209 children, knowledge, attitudes and behaviour were assessed. The final test consists of 32 items, and four items provided by Liu et al (2014) indicate that the test is a performance test.
- Okan and Bollweg (2018) have developed an adaptation of the European Health Literacy Survey Questionnaire (HLS-EU-Q) for children aged 9-10. There were 26 items assessing subjective health literacy with respect to healthcare, disease prevention and health promotion tested among 907 children. Psychometric analysis is ongoing.

Conclusion

In this chapter, an overview and critical discussion of current approaches towards the measurement of children's health literacy was provided. There is a limited, but growing, number of measurement tools available that can be used to assess different components of children's health literacy. Still, less than half of the instruments (8 of 17) were developed specifically for children, and children were rarely involved in the development process. Therefore, it remains debatable to what extent the available tools adequately capture the facets that characterise children's health literacy. Further research is needed, with a particular focus on participatory and qualitative approaches. Additionally, there is a need for more transparent reporting regarding psychometric properties, the instrument development process and the respective items, to allow for quality assessment, enable advancement of the measures and to increase methodological rigour in this field of research.

More generally, a fragmentation of research approaches on children's health literacy can be identified, expressed as a divide between measures of general health literacy and measures focusing on specific health topics. Although this variety of approaches increases complexity in the field of health literacy research, there are good reasons to regard these different approaches as complementary instead of mutually exclusive. Further complexity can be outlined with respect to the very essence of health literacy, that is, its constituent parts as assessed by the different measures. The lack of a universal theory of health literacy in childhood as well as particular research interests for specific components of health literacy manifest in a number of measures that don't share any commonalities at all. It cannot be expected that this problem will be solved in the near future, as the conceptual expansion of health literacy has not yet reached an end point. Instead, calls for

even more sophisticated measures of health literacy will likely lead to greater segmentation in this field of research, but probably also to a better understanding of the processes related to the development of health literacy (in childhood). It will be increasingly relevant for researchers to provide systematic overviews of and to mediate between the different research streams on (children's) health literacy. Already today there seems to be misunderstanding or even a lack of awareness of the multiple approaches, such as general health literacy, media health literacy, mental health literacy, diabetes health literacy or health information literacy.

Last, however, researchers' efforts to measure children's health literacy in multiple ways are acknowledged as a significant contribution to a better understanding of this determinant of health and the pathways to its equitable promotion, to the improvement of effective school health promotion and to the health-related empowerment of younger generations.

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