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Review article

Health literacy in people with intellectual disabilities: A mixed-method literature review

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ABSTRACT

People with intellectual disabilities are exposed to particular challenges within the healthcare system. In particular, elderly people with intellectual disabilities have special needs and require physical activity to prevent age-related diseases. Health Literacy could help people with intellectual disabilities to take participative health-related decisions. To be able to generate knowledge in this area, a literature search was carried out. For this the databases PubMed, Scopus, ERIC, CINAHL, PsycINFO, and Web of Science were searched. The research shows a research gap in the field of health literacy among people with intellectual disabilities. Nevertheless, three categories have been systematized: Barriers for people with intellectual disabilities, health literacy promotion for people with intellectual disabilities, and studies concerning the concept of health literacy for people with intellectual disabilities. The studies found emphasize the importance of a target group specific health literacy concept for people with intellectual disabilities and a need to involve health professionals and adequate communication. In addition, conceptualisation considerations should take into account the specific skills and social context factors of people with intellectual disabilities. Furthermore, the results show that there is an urgent need for a target group-specific definition and measuring instruments.

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Introduction

This article presents the current state of the scientific literature related to health literacy in people with intellectual disabilities (ID) and, to our knowledge, it is the first review that directly relates to health literacy. It focusses on the scientific understanding of health literacy for this special vulnerable group. We refer to the definition of health literacy of Sørensen et al. [1], which reflects the public health perspective and has been developed on the

basis of 17 different definitions: “Health literacy is linked to literacy and entails people’s knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course” [1]. The public health perspective is particularly recommended for the target group of people with intellectual disabilities, because it broadens the concept by many aspects and not only focuses on pure literacy skills. Social and personal determinants of

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this target group can be given special consideration in this definition as they can have a great influence on a person's health literacy. Findings are discussed in terms of health literacy with a focus on physical activity and the group of elderly people with ID.

The group of people with ID is at an increased risk of chronic diseases, cardiovascular diseases and obesity [2]. As a result, there is an increasing need for nursing care in this field. Additionally the life expectancy of people with ID has increased in the last decades and hence, an increased presence for age-related diseases in this group can be verified [2]. Research suggests that they may age differently based on the nature and severity of their disability, coexisting health problems and chronic illnesses. This presents health professionals with particular challenges. There is also evidence that people with ID tend to experience age-related health problems earlier, including incontinence, difficulty swallowing, sensory loss, adaptability losses and cognitive decline [3], as well as oral motor problems and dental problems, fractures, fatigue, pain, arthritis, musculoskeletal deformities, decreased walking ability, progressive cervical degeneration and a higher risk of developing osteoporosis [4]. This risk is often increased by reduced physical activity during the person's lifetime and engaging in less activity compared with members of the general population. Although data gives only good hints to support that statement [5], there is evidence that most people with ID are not performing sufficient physical activity in everyday life according to the recommendation of the World Health Organisation [6]. A positive effect of physical activity on prevention and health preservation has been proven mainly in the diseases mentioned above [6].

Due to reduced communicative and cognitive abilities, reduced reading and writing skills and reduced self-perception, people with ID often have limited access to the resources [7] which are needed to acquire knowledge of health-related subjects and to appraise and apply health related information. These aspects show that the group of people with ID is a vulnerable group in terms of health, health care and everyday life support. Nevertheless, it is of particular importance that health-related information can be understood, appraised and applied in order to make self-determined decisions possible. According to the requirement of the Convention on the Rights of persons with Disabilities [8], which has been ratified by 175 states and affects more than 650 million persons, people with ID have the right to make self-determined decisions. Health-related decisions in particular could have wide consequences for everyday life [1] in terms of health promotion or health preservation. Therefore, people with ID should be able to make informed self-determined decisions and be supported by carers and caregivers. The concept of health literacy focusses on competencies and resources that are important to make self-determined health-related decisions. Health literacy refers to the personal characteristics and social resources needed for people to access, understand, appraise and apply information to make decisions about their health [1]. Furthermore, Health Literacy also provides the necessary basis for making decisions about health care, disease prevention and health promotion [1]. Several

studies have shown that people with low levels of health literacy are exposed to a greater risk of falling ill, have a reduced life expectancy, receive inappropriate care, more frequently find themselves in in-patient hospital care, and have poorer disease management and health maintenance skills [9–13].

With reference to the results of the clinical studies mentioned above, a target group-specific health literacy concept might strengthen the participation of people with ID in health-related decisions. It could also be useful for health promotion and counteract the outbreak of chronic diseases, obesity and early-onset age-related diseases. For this, it is necessary for people with ID to be able to participate in decisions, for example to promote physical activity, and to include the necessary health-related information for this purpose. In addition, special attention should be paid to older people with ID, since through years of institutionalization and obsolete education systems, they have to learn how to deal with health-related information in a self-determined way.

People with ID have specific health-related resources and a higher prevalence of comorbidities, which might be better managed with health literacy. Therefore, this article generates insights on the issue of the state-of-the-art health literacy research for people with ID.

Materials and methods

The aim of this mixed-method-literature-review is to examine the literature and provide an overview of the current research on health literacy and people with ID based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses [PRISMA] guidelines for ensuring high quality and transparent reporting of reviews [14]. This review will answer the following research questions: (a) how and to what extent is the topic of health literacy among people with ID represented in scientific literature? and (b) how is health literacy discussed in the literature affecting people with intellectual disabilities and how is it used for people with ID?

Search strategy

From February to July 2018, six bibliographic databases were searched, including PubMed, Scopus, the Educational Resources Information Centre (ERIC), the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, and Web of Science with English search terms. The databases were deliberately selected to include various scientific disciplines (educational science, psychology, nursing science, medicine and health), while two databases were used for multidisciplinary research (Scopus and Web of Science). According to the research question, a sensitive search approach was used to capture as much relevant literature as possible about health literacy concerning people with ID. Search terms were defined broadly and adapted to specifics of the databases: health literacy AND (intellectual OR learning disabilities) and wildcard characters were used to increase the sensitivity of the

searches. The search terms were generated by examining typically used and broad key words. Health literacy is a multidimensional construct. Our focus lies on a general concept of health literacy, and therefore we did not take the different dimensions into account. Intellectual disabilities and learning disabilities are both used to define our target group according to language background (English or American). These key words were checked with MeSH (Medical Subject Heading, controlled vocabulary search terms for medline). The searches were not limited to any publication time frame, research design or peer-review criteria (e.g., dissertations were included).

Screening process

Two researchers (CG & DB) independently searched the databases using identical search algorithms for the respective databases, and then analysed the data. Grey literature was not taken into account. The search identified $n = 848$ publications (see PRISMA Chart 1). After removing duplicates ($n = 135$) and book (chapter) ($n = 92$), 621 titles

and abstracts were screened. Articles were eligible if they: a) were fully available in English; b) mentioned the term health literacy; c) apparently offered relevant content for the group of people with ID. Publications, for which the researchers reached a differential decision, were discussed with the extended research team (all authors) and if necessary assessed again until consensus was reached. A total of $n = 37$ articles underwent full-text analysis. Finally, all articles not matching the inclusion criteria ($n = 25$) were excluded, yielding $n = 12$ articles that mentioned health literacy in people with ID. Moreover, we used the “snowball search method,” going through the reference list of the 12 included articles to find other relevant articles. This search was unsuccessful and no further article could be found. Due to our goal ‘mapping the state of the art in health literacy research’, not all quality standards as outlined in the PRISMA guidelines applied to our research question, e.g. risk of bias in and across studies. The quality of included studies were also discussed at this point. Following our research question and the sensitive search approach, no exclusions were made.

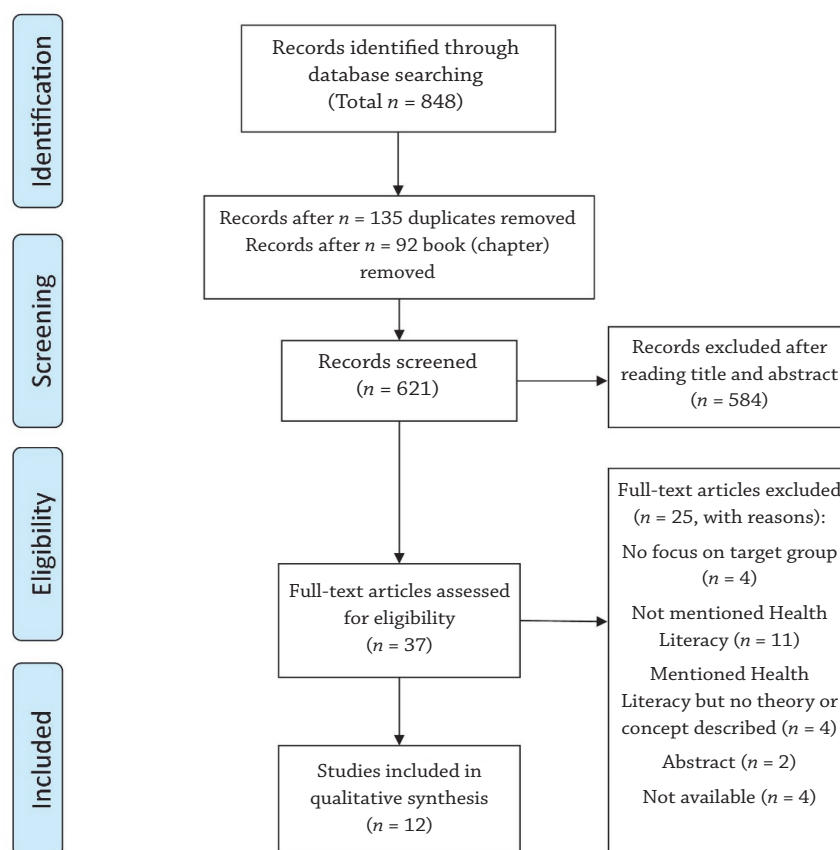


Chart 1 – Flow diagram of the search strategy

Data analysis

Data were analyzed in three steps. First, information was recorded for all included studies. For an overview, the articles were categorized in a second step according to research categories. Finally, included publications were scanned for definitions, understanding and concept of

health literacy used for the target group. In this third step, the articles were coded and discussed with an inductive approach. For this purpose, both researchers scanned the articles and discussed a meaningful categorization according to the research question (see tab. 1). Basic data and key information of the articles were synthesized along the categories in a narrative way.

Table 1 – Results found on the basis of the search strategy

Authors	Year of publication	Title	Key information
Bergström et al. [23]	2013	A multi-component universal intervention to improve diet and physical activity among adults with intellectual disabilities in community residences: A cluster randomised controlled trial.	Intervention; Three component intervention to improve diet and physical activity measured by pedometry, BMI, waist circumference, dietary, quality, satisfaction and work routines. A cluster randomized controlled trial was conducted with both residents and caregivers ($n = 130$). Of seven outcomes, two were found with significant positive effects.
Bergström et al. [21]	2014	Barriers and facilitators in health education for adults with intellectual disabilities – A qualitative study.	Clinical trial; investigate barriers and facilitators with the aim of educating people with ID to make self-determined decisions. Qualitative design within a health course $n = 83$. Data were collected from course leaders.
Boardman et al. [22]	2014	Communicating with people with intellectual disabilities: A guide for general psychiatrists.	Theoretical discourse; Examined communication aspects between people with ID and clinicians and service providers in psychiatrics. Suggestions are made to active listening and personally tailored explanations with the aim of increasing the patients' benefit from service use.
Cardol et al. [16]	2012	People with mild to moderate intellectual disability talking about their diabetes and how they manage.	Clinical trial; Examined the experiences of people with ID having diabetes. Qualitative interviews were conducted ($n = 17$). As a result, there was a lack of information, communication and support resulting in a feeling of loss.
Chinn [27]	2014	Critical health literacy health promotion and people with intellectual disabilities.	Theoretical discourse; Describes the health literacy concept based on Nutbeam [26] three component model for people with ID. Discuss and advocate the critical health literacy level for people with ID to offer opportunities to empowerment and self-decision making for these target groups.
Chinn and Homeyard [17]	2017	Easy to read and accessible information for people with intellectual disabilities: Is it worth it? A meta-narrative literature review.	Review; Provides an overview of the relationship between health-related information, access, understanding and health literacy.
Feldman et al. [25]	2016	Randomized control trial of the 3rs health knowledge training program for persons with intellectual disabilities.	Intervention; Examines the effects of health knowledge training on the health knowledge of people with ID (training group $n = 12$; control group $n = 10$). The training group has significantly higher health knowledge test scores than the control group.
Gray [24]	2018	Increasing participation of people with learning disabilities in bowel screening.	Theoretical discourse; Addresses accessible and understandable health-related information as a necessary aspect for health-related participation. Focuses learning disability nurses as a key agent in access to bowel cancer screening.
Marks et al. [15]	2008	Health services, health promotion, and health literacy: Report from the State of the Science in Aging with Developmental Disabilities Conference.	Conference report; Reports main aspects of the conference. Works out that programs for the promotion of health literacy are needed. These have to focus on communication, since everyday health information is not understandable for people with ID.
Marks and Sisirak [20]	2017	Nurses practioners promoting physical activity: people with intellectual and developmental disabilities.	Theoretical discourse; Describes the need for people with physical activity of support by nurse practioners and health care providers. Above all, attention must be paid to adequate communication. People with ID have reduced knowledge as well as limited skills in appraising health information.
Mastebroek et al. [19]	2014	Health information exchange in general practice care for people with intellectual disabilities- A qualitative review of the literature.	Literature review; describes the health information exchange in GP care for people with ID.
Scott and Haverkamp [18]	2016	Systematic review of health promotion programs focused on behavioral changes for people with intellectual disability.	Review; Systematic review of health promotion programs with a focus on behavioral changes in people with ID.

Results

Study characteristics

The first article that mentioned health literacy for people with ID was a conference report in 2008 [15], and from 2012 the term has been used in different ways. Most of all ($n = 4$) theoretical discourses of health literacy could be found (Table 1). However, a further look shows that health literacy for people with ID is mostly used to describe barriers to health care or possible health promotion, but only one has its main focus on conceptualizing health literacy regarding special needs of people with ID. It is obvious that most studies that comment on the health literacy level of people with ID have assumed that the level of health literacy within this group is very low. None of the studies mentioned a special reference source for this statement. Overall, most studies are from the health professionals perspective and only a few directly questioned or focused on people with ID [e.g. 16].

Barriers for people with ID

A total of four articles focus on difficulties or barriers that prevent people with ID from using health-related information to make a self-determined health-related decision possible. The cause for these barriers is assumed to be a reduced knowledge of health, a lack of self-advocacy, and environmental and attitudinal factors [17, 18]. This can be overcome by the support of other people. These can be either GP's or health care providers [19, 20], or health course leaders [20]. The authors conclude that improved access, communication and knowledge can strengthen both the health literacy and the health-related participation of people with ID.

Promoting the health literacy of people with ID

Strengthening health literacy could lead to more health-related participation [15, 22, 23]. However, it is important that information is accessible and understandable [24] [16] and the health-related knowledge is sufficient [23, 25]. People with ID often have reduced health related knowledge and difficulty understanding information, so they depend on support from learning disability nurses or GP's [22–25]. In order to provide this support, the communication of health professionals needs to be improved [15, 22, 24]. Furthermore, skills like the capacity to read and write, subjective experiences with the health care system, abilities in using health information, and capacity for informed decision-making must be considered [15]. Two studies report an intervention that uses a training program for people with ID to increase their health-related knowledge to strengthen health literacy [23, 25]. The training program described by Feldman et al. [25], involves the transfer of knowledge in a specific design for people with ID in various areas such as pain, food, body organs, etc. Post and

follow-up tests took place 3 or 6 months after the training. Although it is emphasized that health literacy has a major impact on health outcomes, health literacy is included neither in the research findings nor in the test variables. In another training program, a total of ten units focused on healthy food and physical activity. While accurate research on the BMI and the number of steps per day took place, health literacy was not included in the measurements [23], it was only mentioned to give the theoretical framework for this study.

Target group specific health literacy conceptualisation

Since there is only one article dealing with ID on the conceptual level with health literacy, this is described in more detail here. With regard to Nutbeam's tripartite model [26], Chinn [27] criticizes the way in which the discourse around health literacy for people with ID does not go beyond the functional health literacy domain. This becomes apparent from the deficit-oriented perspective that is often taken on health-related issues. She further criticizes that based on this functional perspective, health-related information is changed into seemingly easy-to-read language, and interventions are developed for time-limited and very specific settings, but none of these measures address the real need for support of people with ID.

Health promotion programs for people with ID often refer to communicative skills such as cognitive and social skills. However, these interventions do not live up to the claims of people with ID when it comes to sharing health-related information. Moreover, interventions that affect health-related communication strategies are very rare. The domain of critical health literacy is not represented for people with ID. Chinn [27] concludes that the discourses that focus on the incompetence of people with ID in terms of cognition or social skills prevent the further development of health literacy for people with ID at a critical level. Of course, it requires specific skills, but to strengthen them requires that the perspective of people with ID must be sought and their experience must be incorporated into the development of concepts.

Discussion

People with ID are a high-risk group for chronic diseases and especially comorbidities. They have specific health related resources (such as communication or reading and writing skills), which might be better managed with health literacy [15, 25]. Therefore, the aim of our review is to map the state-of-the-art health literacy research for people with ID. For this, the following aspects will be discussed: extension of the topic of health literacy among people with ID, concepts of health literacy for people with ID, measuring health literacy in people with ID and, physical related health literacy and the elderly with ID-opportunities for health literacy research.

Extension of the topic of health literacy among people with ID

Compared to studies regarding general health literacy, the health literacy research on people with ID is marginal.

Health literacy has become more important over the last few decades, which can be seen in the number of results in PubMed, (see Chart 2). In 2017, there are nearly 400 articles. The articles included in our review have the highest numbers of publishing in the year 2014 ($n = 4$).

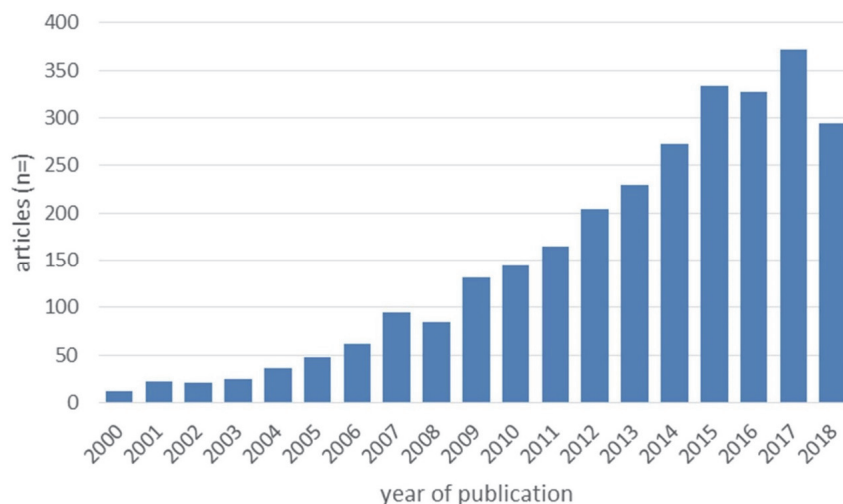


Chart 2 – Number of listed articles that included “health literacy” in the title, PubMed search (22nd July 2018)

The variety of articles may also be due to the fact that health literacy is defined for different health-related areas, populations and contexts [28]. It must be remembered that the concept is still not based on a common definition and that no standardized measurement tools have been developed. This means that health literacy is not a fixed term and has a dynamic development. On the one hand, the concept of health literacy should not be fragmented and represented by scientific research that can be translated into many contexts to make it generalizable [28]. On the other hand, specific health literacy concepts offer great advantages [29], which also apply to research in the field of ID. As a result, the development of interventions and specific measuring instruments has a certain need [29], which will be discussed in more detail below.

Concepts of health literacy for people with ID

All studies mention the importance of pursuing further research focusing on health, access and understanding of health-related information or remaining resources and support needs. Only two studies [19, 21] mention that health literacy is an important aspect in making informed decisions and could help the target group developing empowerment. Marks et al. [15], in a more functional approach to health literacy, note that reading and writing skills and the ability to use information must be taken into account. What the concept of health literacy can mean for this target group and how it can be conceptualized on this target group basis is discussed only by Chin [27]. Chinn sees a great opportunity for people with ID in the concept of critical health literacy. Hence, it should focus on the perspective of people with ID, their own experiences

and the individual social context. Research on health literacy is now well advanced in both clinical studies and conceptualizations. Health literacy is increasingly seen as a crucial factor in terms of health and health-related outcomes and is considered a requirement for patient participation and empowerment [1, 30]. This is different in the studies that deal with health literacy and people with ID. Here, health literacy is often understood as the competence of health, or equated with health-related knowledge [25]. Thus, the concept of health literacy does not go beyond a purely functional understanding in people with ID [15]. Chinn [27] is the only one who encourages a discussion at the conceptual level and the discourse on the conception of a critical health literacy domain. In addition, some studies claim that people’s ID health literacy is low, but there is no scientific evidence of this finding.

What the results show is a lack of health-related knowledge and representation for one’s own interests. Furthermore, the studies show that environmental and motivational factors can influence it. A public health perspective on the health literacy concept is therefore necessary in order to integrate exactly these factors into the concept. The discussion on a suitable concept for people with ID should therefore go beyond a functional understanding of health literacy and include more than written language skills and health related knowledge. There is an urgent need for conceptual scientific debates on health literacy that include people with ID, their experiences, perceptions, resources, and social contexts. Only in this way is it possible to develop the first step towards the concept of health literacy for people with ID that includes a critical health literacy level.

Measuring health literacy in people with ID

The second step should be the development of target-group-specific measuring instruments that provide information on the health literacy level of people with ID on a scientific basis. For this, however, it is necessary to take into consideration the perspective of people with ID. In some of the studies found in this review, people with ID were not directly interviewed, but other groups of people gave information about people with ID. Thus, insights can be generated that can make statements about what different professional groups or caregivers assume about the knowledge or competencies of people with ID. However, to include experiences and needs, as well as individual views on the further development of the health literacy concept, it is important to directly involve people with ID. Considering all the special features of the target group, it is possible to discover their perspective in interviews [31, 32]. When health literacy is a prerequisite for participation and self-determination in health-related issues, it is especially important not to interview third persons, but to directly involve the target group. There is an urgent need for measuring instruments that can be used in a standardized way for people with ID to examine health literacy. It is possible that inclusive research could help to develop these measurement tools and meet all of the target group's resources and needs [33]. To ensure that health literacy is collected and not just knowledge or literacy skills measured, a public health perspective should serve as the basis for the development of measurement tools in people with ID.

Physical activity and the elderly with ID – opportunities for health literacy research

Some studies report a poor health status of people with intellectual disabilities and attribute this to decreased physical activity. The results of some of the included studies support this statement [18, 23]. Interventions to improve Physical Activity in people with ID have the capability to improve health in this vulnerable group [6]. For this, it is useful to develop health literacy in people with ID regarding personal and social skills, and to offer interventions in plain language and within a supportive health environment [6]. As described above, people with intellectual disabilities develop age-related symptoms earlier than the normal population. This is particularly problematic in terms of the decreasing resources of the healthcare system and the additional time needs of people with intellectual disabilities for investigation, testing and communication [15]. As the studies mentioned above have shown, people with intellectual disabilities need special health-related information in order to be able to make informed decisions.

Improved and early health education and empowered health literacy could help in gaining control over health and preventing chronic illness. Especially for the group of the elderly people with ID, health care programs must be developed that incorporate the special life experiences, skills and resources of the elderly [15]. In the studies presented here, the group of the elderly with intellectual

disability is represented very rarely. There is a research gap regarding older people with intellectual disabilities and health literacy, as well as for physical activity in this group. The above aspects clearly show how important health literacy can be for this particular group in order to improve or maintain the health status and to ensure adequate end-of-life care [15]. Nevertheless, a clear understanding of the health literacy concept and the consideration of individual resources and contexts are missing, as our findings have shown. These should be used to target studies that capture the perspective of people with ID, and understand and analyse their needs as well as their everyday-life structures. Then it may be possible to develop a health literacy concept which provides the basis for target group-specific measurements, which can be modified for health promotion e.g. in the fields of physical activity and the elderly.

Limitations of the study

It is necessary to acknowledge several limitations. In our search strategy we used the search term 'health literacy,' which is a multidimensional concept. Articles that do not mention 'health literacy' are not included, and therefore some articles which address elements of health literacy but do not use this term were excluded. The search term 'mental retardation' is not used because this term is outdated. For all eventualities, we checked the search term in combination with health literacy in June 2017, and matched the hits with our first search via the management software citavi 6. No relevant articles were found. We have discussed quality criteria, but have not sorted articles due to poor quality. The reason is that in the quality of studies concerning people with ID is often low, mainly due to small sample sizes or not testing measurement tools regarding validity and reliability. Therefore we would not risk exclusion criteria that are too strict. What is also missing is a closer look at how included articles define ID. The term is mostly presupposed and the heterogeneity is referred to in the discussion.

Conclusions

Overall, the included studies found emphasize the importance of a target group specific health literacy concept for people with intellectual disabilities. In addition, conceptualization considerations should take into account the specific skills and social context factors of people with ID. Furthermore, the results also show that caregivers and health care providers are very important for the dissemination of health-related information. Therefore, the factor of the communication of health care provider and caregivers should be included in the conceptualisation of health literacy in people with ID. The communication is considered to be particularly important. A target-group-specific health literacy concept should include programs to strengthen the communication of caregivers, and health literacy should be developed among nurses and health care providers.

Above all, it is important to avoid a deficit-oriented and medical perspective, and to adopt a broad public health perspective. Only in this way is it possible to place literary skills and pure knowledge into the background, and social as well as environmental determinants into the foreground. It is then possible to react with flexibility to individual contexts and to subjectively strengthen health literacy.

Strengthening the health literacy of people with intellectual disability might benefit those programs and interventions to promote health in this vulnerable group. For future research, it will be important to use health literacy in such a way that people with ID are able to make informed health-related decisions and participate in the health discourse.

Conflict of interests

The authors have no conflict of interests to declare. There were no funding bodies used for this research. The authors are active members of the Institute of Educational and Healthcare Research (InBVG, University of Applied Sciences, Bielefeld).

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