

Medication Literacy for Children and Families

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Abstract

Health and specifically Medication Literacy is important in patient empowerment and in empowering patients and families as effective partners in ensuring optimal health outcomes. While there has is a reasonable body of evidence on this for adults, there has been very little work on medication literacy for children, specifically in terms of effective interventions. Adopting agreed upon nomenclature and developing and validating children’s specific instruments – such as infographics - will be important in moving forward, especially when these instruments can be actively incorporated into eHealth initiatives.

Introduction

Literacy is a set of competencies involving a continuum of learning using written, print, and digital mediums—that can be objectively assessed—allowing the individual to participate fully in the community and wider society [1]. UNESCO operationalizes the measurement of literacy as the ability to both read and write a short, simple statement about one’s own life [2], and global literacy rates have been steadily climbing over the course of this century, e.g. leaping from 21% in 1900 to 86% in 2015 [3]. In general, there is a linear relationship between literacy rates and years of education, but there is a point on the continuum of literacy, where due to several social, geographic, medical, and economic factors, that a person does not acquire a sufficient capacity of reading, writing, and counting, and is therefore considered to be illiterate [4]. What is troubling is that approximately 18% of U.S. adults (~43 million) have low literacy levels, and even in the highest scoring countries for literacy, there are alarming proportions of adults still performing at this lowest level, where 5% of adults in Japan and 11% in Finland perform at or below level 1 literacy [5].

The relationship between reading ability and health, known as “health literacy”, broadly reflects the skills and competencies required to operate within the healthcare environment. Results from a systematic review of health literacy and child health outcomes show that people who read at low levels are generally 1.5 to 3 times more likely to have an adverse health outcome (including parent and child outcomes) when compared with those who read at high levels [6]. The most current definition for health literacy has been put forth by the International Union for Health Promotion and Education (IUHPE) Health Literacy Global Working Group, who offered the following: “health literacy is an asset that can support a wide range of health actions to improve health and well-being, to prevent and better manage ill-health”. More broadly, health literacy is determined by both individual and social factors, including the individual skills necessary to function within the healthcare system, and the ability to make appropriate health care decisions with a circle of care that positively impacts health. These skills include, but are not limited to, print literacy (the ability to read and understand text and locate and interpret information in documents), numeracy (the ability to process quantitative information), and oral literacy (the ability to listen and speak) [7, 8] (see **Figure 1** for other pillars of literacy).

Although a useful construct, our ability to measure health literacy as a single variable is limited. Nonetheless, research to date has focused mostly on reading ability as a proxy measure for health literacy [9]. In a systematic review on health literacy, it was found that although there are several well-validated tools to

measure health literacy, the majority of high quality research on this topic focuses on using the Rapid Estimate of Adult Literacy in Medicine (REALM), or the Test of Functional Health Literacy in Adults (TOFHLA), including the short version (S-TOFHLA). Within the body of literature reviewed, the authors concluded that no one instrument was better than the other (i.e. correlation coefficients, $r = .74$ to $.88$) at predicting the overall impact of adult health literacy on one's ability to function in the health care environment, or on predicting overall impact on health outcomes of the adult or child [10]. More recently, a screening test called the Newest Vital Sign (NVS)—using a nutrition-label approach—has been validated and has several advantages, *i.e.* it is available in Spanish, whereas the REALM is not, it can be administered much more quickly and assesses quantitative-numerical questions better than the TOFHLA, and it provides better discrimination of health literacy skill levels [11]. In a global sense, however, the high correlation between these health literacy measurement tools suggests that they measure essentially the same underlying construct where the assessment of low health literacy is predictive of poor health outcomes [12].

In contrast to these well-validated tools and related body of research in adults, the work on assessing health literacy in children is still in its infancy. A recent systematic review by Okan et al. (2018) on child and adolescent health literacy measurement outlined up to 15 different tools found in the literature [13]. Comprised of both generic and specific health literacy instruments, the majority of the tools tested children from 11 to 18 years of age, but there were 5 tools that measured health literacy of children younger than 11 years old. Although it is promising research in child health literacy is growing, the current body of evidence shows that the available tools are not adequately measuring and/or depicting health literacy. Within the current body of research, and with the understanding that the work on child health literacy tools and outcomes is preliminary, higher levels of health literacy have been associated with better health behaviors in adolescents [14], whereas, lower-than-average literacy among adolescents seems to be related to risk-taking and violent behaviors. Specifically, after adjusting for sex, race, and age, children and youth who have low health literacy have a significantly higher odds of carrying a weapon (2x the odds), being threatened by a weapon at school (2x the odds), being in a fight that resulted in injuries requiring treatment (3x the odds), and missing school because of feeling unsafe (2x the odds) [15]. It should be noted that there are very likely other societal factors that co-vary with low health literacy, so these findings must be interpreted with caution.

Examining findings from eight countries from the first European comparative survey on health, it was shown that almost half of the respondents (47%) had limited (insufficient or problematic health literacy) [16]. Similar results have been shown in earlier studies from the United States (US) and Canada. The survey conducted by the former Canadian Council on Learning estimated that about 2/3 Canadian adults and 9/10 of seniors lacked the capacity to obtain, understand and act on health information and services and make appropriate health decisions on their own [16]. According to the US Department of Health and Human Services, 9 out of 10 adults have difficulty using the everyday health information that is routinely available to them in different settings in their daily lives [17]. This body of research indicates that low parental literacy is related to worse health outcomes, particularly for young children. It is in this context of low health literacy where a main area of study emerges as paramount when discussing the well-being and safety of parents and children, and that is, medication literacy. Studies have shown that adult patients with low health literacy levels are often unable to name or describe how to use their current medications, have a limited understanding of their medication and the associated side effects, and are often less likely to ask questions to their pharmacists [18, 19]. In order to properly consume their medications, individuals are required to read their medication labels and the associated medical information, comprehend what to do in case of a missed dose or side effects, and sometimes they have to calculate the proper dose to consume. Furthermore, individuals not only have to be able to take their medication and be able adhere to the full course of their own therapy, but they also have to take care of the medication schedules for their children. To be sure, the impact of low health literacy is drastically precipitated when the care of children is taken into account, as pediatric patients are susceptible to medication error due to lack of appropriate pediatric formulations, the liquid nature of pediatric dosage forms, the availability of non-standardized devices for measurement, dose calculation mistakes, ignorance of caregivers, and inadequate information and counseling by physicians [20,

21]. In a sample of 17 845 respondents, children of parents with low health literacy also have been shown to have a 32% higher rate of depression when compared to parents with high health literacy [22], and low parental numeracy is associated with higher body mass index and childhood obesity [23]. More than this, the impact of low medication literacy cannot be underestimated in the context of disease management. A summary of the effect of low health literacy in the context of several common chronic conditions in pediatric populations is presented in **Table 1**.

The use of the health literacy concept in the context of pharmacy and medication is not new, but formal definitions of health literacy in the context of medication use have only been operationalized in the past decade [24, 25]. More recently, via a thorough Delphi analysis, the definition of medication literacy has been updated with a shift away from the focus on the individual-level, patient specific concept of medication literacy. Thus the most recent definition of medication literacy now highlights the importance of healthcare providers and industry, and has been operationalized as “the degree to which individuals can obtain, comprehend, communicate, calculate and process patient-specific information about their medications to make informed medication and health decisions in order to safely and effectively use their medications, regardless of the mode by which the content is delivered (e.g. written, oral and visual)” [26]. In the public health context, medication literacy is integral to the safe and effective delivery of health care. Medication literacy is in fact a sub-element of health literacy, and both sharing over-lapping concepts such as numeracy, visual literacy, and computer literacy, for example. It should be noted that the scope of the overlap of these shared competencies between health literacy and medication literacy seen in **Figure 1** are not to scale and are only meant to serve as a heuristic. As an example, recent work by Gutierrez et al. (2019) reported an association between numeracy and medication competence that was independent of the influence of general health literacy, suggesting that numeracy skills represent a unique component of medication literacy. To date there is only one validated tool to assess medication literacy, The Medication Literacy Assessment tool (MedLitRxSE). The MedLitRxSE was developed by Saucedo et al. (2012) to provide researchers and health care workers with a tool to evaluate the patient’s ability to access, understand, and act on information related to medication use. The MedLitRxSE assessment tool is directly correlated with health literacy in adults, but being a new tool, to our knowledge no studies have been done in caregivers or adolescents [25]. As the concept of medication literacy evolves it will be important to advance with assessment tools that take into account elements that describe the broader outcomes and goals of medication literacy; highlighted in **Table 2** are key elements that must be taken into consideration when developing new reliable tools to quickly and efficiently assess medication literacy.

It is clear that improving the patient’s ability to understand and make appropriate decisions depends on improving their health literacy and ensuring the information is both accessible and understood. It is not possible to visibly tell who has low healthy literacy by simply looking at the individual, and as a result, it should be assumed that most patients will have difficulty understanding health information. One way to help mitigate risks in misidentifying differences in health literacy is to use a universal precautions approach [27]. With this approach precautions are best practices instituted uniformly in a standardized fashion to improve communication and participation for all patients regardless of health literacy [28]. Universal precautions recognize the contribution of health literacy to health care disparities and seek to improve access to health care systems for all users [28]. Indeed, due to the high variability in health literacy levels across communities and cultures, using the clearest language possible is paramount. Health care providers should also assess in real-time if the clear communication is working and incorporate additional targeting and tailoring methods as necessary to ensure that patients receive the information they need to make appropriate health decisions. Even if patients do receive usable spoken and written information, it could be argued that this information is still not sufficient even with adequate levels of health literacy. Therefore, in addition to this passive information approach, active strategies that attempt to change a behavior or thinking of an individual must also be considered in an effort improve health outcomes of the parent and child.

Active interventions are strategies that attempt to change a behavior or thinking of an individual through patient involvement, whereas, passive interventions are strategies where a patient is not required to participate or respond to the intervention. An example of an active intervention is an educational “teach-back”

program—where the patient restates small pieces of information such as how to fill liquid to a certain volume, for example. In a recent meta-analysis of 21 active interventions studies that reported data on medication knowledge, 16 studies showed that active interventions resulted in a statistically significant improvement [29]. The Ask Me 3 is another active intervention commonly employed, and by encouraging patients to become active members of the health care team, patients have consistently reported higher satisfaction and found this intervention helpful in learning more about their medical condition or illness in their visit to the doctor [30]. An alternative method to help patients with low medication literacy to navigate the interconnected lanes that pave the health care system is the “show-back” method—another example of an active intervention—where a patient demonstrates how they would follow the pharmacist’s medication instructions for administering an asthma inhaler with a pump, for example. This type of patient learning has proven to improve knowledge and adherence and can lead to improved health outcomes. On the other hand, an example of a passive intervention would be when a patient is sent home with a set of simplified medication instructions on information leaflets, supplementing verbal counseling with written instructions [31, 32]. The importance of this type of communication can be explained using the example of medication-related information at hospital discharge, where the parent must navigate through the discharge plan with a child already in duress. Pediatric populations are confronted with a myriad of complex information at hospital discharge due in part because of the use of unlicensed (e.g. compounded by pharmacists), off-label medicines, and weight-based dosages. Indeed, the importance of written materials can reinforce verbal communication and improve recall and satisfaction among parents of children being discharged from hospital [33, 34]. There is good evidence that educational leaflets with accurate, easy and comprehensible wording, as well as picture-based instructions, are good ways to support verbal medical advice as a passive form of communication [35-37]. Successful results have been noted by incorporating leaflets for eczema action plans, which are individualized tools to help caregivers and patients self-manage eczema [38]. Furthermore, similarly beneficial child outcomes have been attained by incorporating action plans for anaphylaxis [39], where a systematic review found that anaphylaxis action plans directed at the parent and child can have the potential to reduce the frequency and severity of further reactions, as well as improve knowledge of food avoidance techniques [40].

With the understanding of the current climate of low health-and-medication literacy levels across much of the world, it is important that the written information be accessible and, according to a large body of research, be at no higher than a grade 6 reading level [41]. In fact, from a recent systematic review by Wali et al. (2016) of interventions to improve medication information for low health literate populations, written information was the most commonly used intervention [29]. The authors purported this may be explained by the fact that current pharmacy practice legally requires pharmacies to provide patients with written medication information. Of the 47 studies published between 2005 and 2014, successful interventions other than simple written information fell into four other categories of medication information: verbal information, label information, reminder systems, and educational program/services. The aim of these health communication strategies and information systems is to increase knowledge, attitudes, or behaviors. In relation to medication safety and literacy, well-tested and validated pictograms should also be included as a strategy to improve medication literacy. According to the International Pharmaceutical Federation (FIP) guidelines for the labels of prescribed medicines, the use of pictures to convey medical directives should not be used single-handedly and should always be combined with written instructions. The guiding theory of pictogram use in any field of study is that when exposed to an image, the verbal memory may be triggered reinforcing memory traces and subsequent recall; in order to do so, the message needs to be clear, appropriate for the intended audience, and must focus on actions rather than information. Clear and well understood pictograms or infographics have been shown to have clinical importance with the potential to improve a patient’s comprehension and recall of drug-related information [42, 43]. More than this, in a recent systematic literature review by Sletvold et al. (2019), the authors found that of the 17 studies included, 10 studies (58.8 %) reported a statistically significant effect of pictogram- containing interventions on patient adherence to medication therapies [44]. Taken together, given the current worldwide COVID-19 pandemic, the role of developing culturally-specific pictograms will no doubt be brought to the fore in our efforts to bring novel health and medical literacy information out to the public.

Self-monitoring, generally defined as the awareness of symptoms through measurements, recordings, and observations, has also been shown to help with medication literacy. With the near ubiquitous nature of digital technology even in third world countries, self-monitoring tools are being applied with newer digital interventions focused on the portability and accessibility often seen with mobile technology. For example, the use of mobile technology with the combination of an electronic chip on a blister pack has been employed to improve medication adherence, where patients were reminded to take their medication through a text message if the medication was not taken out of the blister pack [45]. It is clear that as a result of the broad access to the internet and mobile devices, much of the population uses the internet to search for health-related information [46]. Mobile health apps are dramatically changing how patients and providers manage and monitor chronic health conditions, especially in the area of self-monitoring [47]. To be sure, adolescents are heavy internet users, where some liberal estimates have found that 98% of adolescents use the internet every day [48]. Developing eHealth literacy skills and improving mobile medication literacy information among our youth is important because they consider the internet their primary and best resource with which to find health information [49]. Considering that previous studies have reported a significant relationship between internet use and higher eHealth literacy levels among adults [50], one can postulate precipitously greater eHealth benefits in the youth populations due in part to the combination of adept computer skills and the incorporation of eHealth into educational curricula at younger ages. Clearly, the importance of a universal precautions-based approach in designing eHealth services will be integral to ensuring the delivery of this type of information. Smith et al. (2019) have paved the way to clearly identify these barriers and disparities in the accessibility to digit health information [28].

Conclusions

It is only recently that we have seen attempts to conceptualize health literacy in the context of medication use by using terms such as medication literacy. To advance the field of medication literacy, we advise other groups to adopt the updated nomenclature as per what has been recently defined by our group [26] as “the degree to which individuals can obtain, comprehend, communicate, calculate and process patient-specific information about their medications to make informed medication and health decisions in order to safely and effectively use their medications, regardless of the mode by which the content is delivered (e.g. written, oral, and visual).” While it is true that we should strive to improve health literacy on a global scale, it does not matter whether people have high or low levels of health literacy if they are not provided information that is accessible and easy to understand. Indeed, there are tens of billions of dollars spent annually on developing medicines and it is left to the clinician, nurse, pharmacist, and patient to navigate these winding and inter-connected roads of health-and medication literacy. The effectiveness and safety of medicines cannot be maximized unless patients understand their role in the medicine-taking process. Moving forward, it is crucial that front end health care workers recognize inter-individual differences in health literacy, and whenever appropriate, that they address the medication literacy challenges they may face when dispensing medications or providing drug information to patients.

There are well-validated tools to assess health literacy in adults, but there are far fewer tools to assess health literacy in children. For medication literacy the tools are far less developed, especially so for the youth. Because pharmacists are an accessible resource for medication information, their position in the health care continuum allows them to apply medication literacy tools to ensure proper counseling and the responsible use of medicines. Clear and easily understood pictograms or infographics should be included as part of each drug information leaflet, as these forms of passive information have been shown by multiple studies to have the potential to improve comprehension and the patient’s recall of drug-related information. Effective spoken and written communication of information about medicine to patients is crucial to the success of treatments, and in this internet age of near total connectivity, the importance of incorporating active forms of eHealth communication into health-and-medication literacy will be areas of future research. With this in mind, we believe that pharmacists are well situated to ensure that patients understand their medication regimens correctly, and that they use their medications safely and effectively through the use of literacy-based communication techniques. Because medication literacy has the potential to enhance access to health care services –and especially so for the most vulnerable populations–we believe this to be an important topic

for clinicians, nurses, pharmacists, and more importantly, for children and families.

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