

Linking Health Literacy and Health Disparities:  
Conceptual Implications and Empirical Results

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## Summary

Health literacy, defined as “(...) *the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.*” (IOM, 2004), has been found to be an important concept in explaining differences in health. Limited health literacy has been linked, amongst others, to worse general health (Wolf, Gazmararian, & Baker, 2005), less usage of preventive healthcare services (Bennett, Chen, Soroui, & White, 2009), higher risk of hospital admissions (Scott, Gazmararian, Williams, & Baker, 2002), and eventually higher mortality (Baker et al., 2007). Particular in groups that are afflicted by socioeconomic disadvantages limited health literacy has been found to be more prevalent, thus lending itself as an important factor to consider when talking about health disparities in general.

Research on the concept of health literacy in the last twenty years has largely evolved in the United States (US) and conceptualizations, as well as the development of measurements, have been so far predominantly developed in the US. Only little research has yet focused on its transferability to other contexts to explore whether underlying constructs and relevant measures will show the same patterns. Further, in how far commonly found relationships between health literacy and health outcomes or behaviours will also hold true in other countries than the US.

The work presented in this dissertation sets out to test in how far health literacy can be transferred to other contexts and how far patterns found concur with those found in the US. Further, it aims at contributing to the still ongoing debate on the conceptualization and operationalization of health literacy, as well as on the conceptual pathways that link health literacy to differences in health.

By providing the results of two studies that aimed at validating a short measure of functional health literacy in two different countries, this dissertation provides evidence on the fact that commonly used measures of health literacy are also valid when used in other contexts. Further, that the concept of health literacy and its underlying constructs are transferable to other parts of the world (Part I). Having established a potential cross-cultural and linguistic validity of the concept of health literacy, two

studies are presented that aimed at testing the relationship between health literacy and healthcare costs in a sample of diabetes patients in Switzerland. Thereby, testing whether hypothesized relationships would also hold true in the Swiss context. Further, to contribute to the empirical literature by providing evidence on a still largely understudied relationship in the field of health literacy. Results confirmed hypothesized relationships, showing that lower levels of health literacy indeed were related to higher healthcare costs (Part II).

The dissertation also aims at contributing to the current discussion in how far health literacy contributes to differences in health outcomes. In particular those that are often associated with other social determinants that are closely linked to unjust distribution of wealth or education. In the US for example ethnic and racial minorities have been most often found to be afflicted by the negative outcomes of health. Health literacy as a potential explanatory variable in this relationship has been widely discussed, yet little is known about its exact role in this relationship.

The dissertation presents a conceptual discussion on the relevant issues that may have prevented health literacy to be more systematically integrated into research on disparities and to not fully leverage its potential for interventions in the field.

Further, by means of a systematic review the work at hand aims to outline the current empirical knowledge on health literacy and health disparities. Results of this review indeed point to the fact that little systematic evidence is yet available, due to the lack of systematic testing of potential pathways describing how health literacy contributes to disparities. Further, disparities as such are only seldom sufficiently described in the literature and are predominantly treated as confounders.

Lastly, a study is presented that tested for differences in health literacy by comparing three immigrant groups in Switzerland to the general Swiss population, and explored in how far the interplay between health literacy and acculturation might explain health differences.

This dissertation contributes to the discussion on the conceptualization and operationalization of health literacy by providing evidence on its transferability and that its underlying constructs might be sufficiently applicable to other contexts. Further, the

relationships identified do not only have implications for researchers but for healthcare practitioners and policy makers as well. In particular the relationship found between health literacy and costs has the potential to significantly leverage health literacy as a topic on the healthcare agenda. Finally, by discussing and identifying gaps on current knowledge on how health literacy contributes to disparities, and by identifying differential effects by means of different measures, this work presents a first careful stepping stone on how to systematically disentangle potential pathways linking health literacy to health disparities.

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**Chapter 1**  
**Introduction**

*Sarah Mantwill*

## 1.1 Introduction

In an ever-growing information environment, definitions of literacy need to move beyond the traditional understanding of reading and writing skills, allowing people to merely function in nowadays society. Topics such as financial, media or political literacy have increasingly emerged on research agendas across the world, aiming at understanding how differential conceptualizations of literacy inform individual's understanding and decision-making (Frisch, Camerini, Diviani, & Schulz, 2011).

Health literacy as one research area of interest has emerged more than twenty years ago in the United States (US) and researchers, as well as practitioners all across the healthcare spectrum, are ever since aiming at understanding how health literacy affects health outcomes (Berkman, Davis, & McCormack, 2010). The most prominent definition of health literacy has been brought forward by the Institute of Medicine in the US (IOM) (2004), which defines health literacy as:

*“(...) the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.” (IOM, 2004)*

In the US health literacy has been linked to a number of health outcomes and behaviors. Limited health literacy has been found to be associated, amongst others, with worse general health (Cho, Lee, Arozullah, & Crittenden, 2008; Wolf, Gazmararian, & Baker, 2005), decreased usage of preventive healthcare services (Bennett, Chen, Soroui, & White, 2009; White, Chen, & Atchison, 2008), higher risk of hospital admissions (Baker, Parker, Williams, & Clark, 1998; Baker et al., 2002; Scott, Gazmararian, Williams, & Baker, 2002) and eventually higher mortality (Baker et al., 2007; Cavanaugh et al., 2013). In chronically ill patients specifically limited health literacy has been found to be related to less disease knowledge (Gazmararian, Williams, Peel, & Baker, 2003; Kalichman & Rompa, 2000), less medication adherence (Osborn, Paasche-Orlow, Davis, & Wolf, 2007; Osborn et al., 2011) and less effective disease management overall (Sarkar et al., 2010; Schillinger et al., 2002; Williams et al., 1998).

Even though a lot of questions regarding the precise nature of how health literacy is linked to health outcomes still persist, research on health literacy in the US has started to move beyond the sole exploration of the mechanisms linking health literacy to health outcomes towards understanding how to translate findings into interventions, eventually trying to operationalize health literacy as an intervenable factor (Johnson, Baur, & Meissner, 2011).

## **1.2 The Concept of Health Literacy**

In the US the term “health literacy” was already introduced in 1974. Simonds (as cited by Ratzan, 2010) described health literacy as part of an integrated health education, which was identified as an important healthcare policy issue back then. Still, it was only about 20 years later that health literacy started to be systematically recognized as an influential factor on health outcomes by researchers and policy makers working in the field of health.

However, definitions and conceptualizations of health literacy still largely vary and no commonly agreed definition has been found until today. As mentioned above the most commonly cited definition has been issued by the IOM in the US (2004). This definition refers mainly to individual health literacy skills, focusing largely on the individual’s capacity to access information relevant to his/her health and to act upon it (Paasche-Orlow & Wolf, 2007). Some have argued that this definition is not comprehensive enough, as it does not take sufficiently interactions into account that may occur in the healthcare setting, hence potentially ignoring dynamic interactions between patient, healthcare providers and the system at large (Baker, 2006). The World Health Organization (WHO) for example has defined health literacy not only in terms of individual skills but also as a potential leverage factor to increase empowerment by improving capacities and access to health information (Nutbeam, 2008).

*“Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Thus, health literacy means*

*more than being able to read pamphlets and make appointments. By improving people's access to health information, and their capacity to use it effectively, health literacy is critical to empowerment.*" (Nutbeam, 1998)

Paasche-Orlow and Wolf (2007) describe health literacy similar to this definition. Besides functional skills, such as verbal fluency, memory span and navigation skills, they also describe how the context might interact with individual health literacy, describing health literacy as a phenomenon derived from personal as well as systemic factors.

Nutbeam (2008) delineates the differences in the definitions of the IOM and the WHO as either health literacy being conceptualized as a clinical risk or a personal asset. When described as a clinical risk, health literacy refers to individual skills that may, for example, influence decision-making in the clinical setting. Meaning, if health literacy is limited it will lead to a potential risk in effectively managing and reacting to one's own health needs. Thus, creating the necessity on the side of the healthcare provider to appropriately act upon it (Nutbeam, 2008). On the other hand, if health literacy is defined as a personal asset, it refers to its potential alterability due to, for instance, health education and communication. The purpose of this rather ecological perspective is to empower the individual to exert more control over his/her life and other important social determinants (Nutbeam, 2008).

Other conceptualizations have focused less on the potential pathways on how health literacy leads to health outcomes but have focused on the different dimensions that might constitute health literacy. One of the most commonly cited frameworks differentiates health literacy into three different dimensions with different implications (Nutbeam, 2000). The first dimension is functional health literacy, which refers to basic reading and writing skills needed in the medical context. The second dimension refers to communicative health literacy and describes the potential of being actively involved in the healthcare process by using skills that allow the individual not only to extract relevant information but also to derive meaning from such. The last dimension is related to more advanced cognitive and social skills, which allow the individual to critically

analyze information and use it to exert more control over his/her life and in particular health (Nutbeam, 2000).

Compared to the US still relatively little is known about the concept of health literacy in other parts of the world. In Europe for example research on health literacy is still in its infant shoes and conceptualizations of health literacy are less evolved (Kondilis, Kiriaze, Athanasoulia, & Falagas, 2008). One of the main issues when talking about health literacy in Europe is to understand whether health literacy entails the same conceptual meanings as it does in the US. Knowledge on which conceptualizations and measurements are most appropriate for the European context is still scarce. This issue becomes already evident by solely comparing translations of the term health literacy into other European languages. Whereas for example in German and Danish health literacy is translated as “health competence” (Gesundheitskompetenz/Sundhedskompetence), in French the term still varies between “health knowledge” (Connaissances en matière de santé) and “health literacy” (Alphabétisme en matière de santé, littératie en matière de santé). On the other hand, in Italian the term has been translated with “Cultura della salute” (health culture/knowledge), suggesting that health literacy might be a teachable concept. These differences imply potential different interpretations of the term and consequently its operationalization (Sørensen, & Brand, 2013). European researchers have developed conceptual models that do not claim to be specifically set in the European context. However, one cannot exclude the assumption that these models are based much more in European reality than their counterparts from the US.

Similar to Nutbeam (2000; 2008), Schulz and Nakamoto (2013) for example, conceptualize health literacy along different dimensions. Besides functional health literacy, they describe declarative and procedural knowledge, as well as judgment skills as integral parts of health literacy. Declarative knowledge refers to knowledge an individual can gain by using his/her functional literacy skills and who has it readily available when needed. In the case of diabetes for example it means that a person suffering from it will know that diabetes is a condition that causes high blood sugar levels. Procedural knowledge refers to knowledge in the health context that an individual is able to apply. This does not necessarily mean that one is able to accurately describe

his/her knowledge but that he/she has the skills to accurately use them. In the case of a diabetes patient for example, one may want to think of it as the capability to accurately inject insulin. The last dimension, judgment skills, refers to the capability of an individual to extract and interpret already existing knowledge, which he/she is able to apply to new or different contexts. He/she will make an informed decision using his/her judgment skills in order to gain the maximum benefit with regard to one's own health in any given (new) situation. A diabetes patient on vacation in a different country for example will not be able to identify all foods relevant to his/her diet. However, he/she might be able, based on experiences and knowledge, to extract such things as portion sizes and amount of carbohydrates in order to decide which food items might still fit his/her dietary recommendations.

On the other hand, within the framework of the European Health Literacy Survey (HLS-EU) Sørensen and colleagues (2012) propose a rather ecological model of health literacy. The model refers to the most prominent definitions of health literacy by describing accessing, understanding, appraising and applying health information as the core of the model. These competencies allow the individual to develop knowledge and skills that will permit him/her to navigate the healthcare system throughout the healthcare continuum. Similar to Paasche-Orlow & Wolf's (2007) conceptualization and the definition of the WHO it proposes a model that moves beyond individual skills to a public health perspective of health literacy. Based on this model the HLS-EU was developed, which was the first study that tried to systematically compare and evaluate health literacy across eight different nations and languages in Europe (HLS-EU Consortium, 2012).

## **1.2 Measuring Health Literacy**

Given the relative scarcity of research on health literacy in Europe, little evidence on measurements of health literacy is available. In the US the most common measures of health literacy were developed in the 1990s, namely the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993) and the (Short)-Test of Functional Health Literacy in Adults (S-TOFHLA) (Baker, Williams, Parker, Gazmararian, & Nurss,

1999; Parker, Baker, Williams, & Nurss, 1995). Other measures that have been more recently developed are the Newest Vital Sign (NVS) (Weiss et al., 2005) or the self-reported brief health literacy screeners (BHLS) developed by Chew and colleagues (2004; 2008), which have found wide adaptation in clinical settings in the US. There are many more measures that have been developed to assess health literacy in the clinical setting but none of them has yet received as much attention as the S-TOFHLA or the REALM, often described as the gold standards for assessing health literacy (Haun et al., 2014). Population-based measures, which assess health-relevant literacy skills, have been developed as part of larger literacy assessments in the general population (Haun et al., 2014; Kutner, Greenburg, Jin, & Paulsen, 2006; Rudd, 2007).

In other parts of the world development of health literacy measures is less advanced. It does not come as a surprise that most health literacy measures outside of the US have often been independently developed, given language and contextual reasons. However, surprisingly few efforts have been made yet to systematically adapt and test already existing measures, and even less so to test for possible relationships similar to those found in the US. For language reasons, measures such as the REALM or the TOFHLA have seen some uptake in the UK (Gordon, Hampson, Capell, & Madhok, 2002; Ibrahim et al., 2008; von Wagner, Semmler, Good, & Wardle, 2009) but in other European countries little research has looked into how these measures perform and might be related to health outcomes.

In the Netherlands, for example, some attempts have been made to translate and validate measures that have been originally developed in the US. Fransen and colleagues (2011) for instance translated and tested the NVS, the REALM and the BHLS. It was found that measures were able to distinguish between high and low-educated groups of participants but results also showed that further refinement was still needed to use them in the Dutch context (Fransen et al., 2011; Fransen et al., 2014; Maat, Essink-Bot, Leenaars, & Fransen, 2014).

The BHLS for example, that are a very brief and easy assessment of health literacy by asking participants about their confidence in their skills to read and understand medical information, have seen a little bit more uptake in Europe. They have

been integrated into a number of studies in different countries, including Germany, Greece, Italy, the Netherlands and Switzerland (Altsitsiadis et al., 2012; Diviani, Camerini, Reinholz, Galfetti, & Schulz, 2012; Farin, Nagl, & Ullrich, 2013; van der Heide et al., 2014; Lupattelli, Picinardi, Einarson, & Nordeng, 2014; Verkissen et al., 2014).

In spite of this, the number of adapted and published measures is limited. Further, most studies in Europe did not scrutinize any relationships between health literacy and specific health outcomes. Most of the studies validated the measures by mainly looking at distributions of health literacy levels and potential predictors of health literacy, such as age or education (Fransen, Van Schaik, Twickler, & Essink-Bot, 2011; Haesuma et al., 2015; Maat et al., 2014;). Yet, these studies confirmed findings from the US. People more likely to be afflicted by limited health literacy in Europe were for example older or had lower overall education (Fransen et al., 2011; Martins & Andrade, 2014; Toçi et al., 2014b).

### **1.3 Health Literacy as an explanatory variable**

Those few studies that have actually investigated more specific relationships identified that limited health literacy in Europe shows similar patterns to the ones found in the US. A study from the UK for instance demonstrated that lower levels of health literacy are associated with higher mortality (Bostock & Steptoe, 2012). In the Netherlands it was found that lower levels of health literacy are related to worse general health in the general population (van der Heide et al., 2014).

As mentioned above, studies in the US have shown that chronically ill patients with limited health literacy are less knowledgeable about their disease (Gazmararian, Williams, Peel, & Baker, 2003). In diabetes patients limited health literacy has been, amongst others, linked to less accurate self-management behavior (Kim, Quistberg, & Shea, 2004), worse glycemic control (Schillinger et al., 2002; Schillinger, Barton, Karter, Wang, & Adler, 2006), more frequent hypoglycemic episodes (Sarkar et al., 2010) and worse communication with the treating physician (Schillinger, Bindman, Wang, Stewart, & Piette, 2004). Even though, still in its beginnings, similar results for chronically ill

patients start to emerge in Europe. A study from the Netherlands for example found that diabetes patients with lower levels of health literacy were less likely to effectively manage their disease and to be less knowledgeable about it (van der Heide et al., 2014). Also studies in the UK found that in patients with coronary heart disease lower levels of health literacy were linked to less disease knowledge (Ussher, Ibrahim, Reid, Shaw, & Rowlands, 2010), and in rheumatoid arthritis patients it was associated with increased hospital visits (Gordon, Hampson, Capell, & Madhok, 2002).

In the US health literacy has also often been described as a potential variable able to explain differences in health that are likely to be associated with social disparities such as race, ethnicity or education (Paasche-Orlow & Wolf, 2010). Research on health literacy has indeed shown that those groups that are more likely to have lower levels of health literacy are often also more likely to be of lower socioeconomic status and to come from socially disadvantaged groups (Kutner, Greenburg, Jin, & Paulsen, 2006). In Europe, however, this relationship has been largely overlooked so far and only minimal evidence is available on the relationship between social determinants of health outcomes and the role of health literacy in this relationship.

The above-described literature shows that evidence on how health literacy is associated with health outcomes outside of the US is still limited. Even though only European patterns were described, the same holds true for other places, such as Asia (Asian Health Literacy Association, n.d.) or Latin-America and evidence on health literacy in these parts of the world is still far away from being conclusive.

## **1.4 Main objectives of the dissertation**

This dissertation aims at contributing to the conceptualization and measurement of health literacy and to potentially disentangle it from other adjacent concepts in order to identify how it contributes to health outcomes.

As previously described measures on health literacy outside of the US are still scarce and there is still a lack of knowledge on whether already commonly used measures, that were initially developed in the US, are also applicable to contexts outside of the US. The adaptation of already existing measures would not only provide data that

would allow researchers to systematically compare health literacy levels across countries but would also shed light on whether health literacy entails the same conceptual meaning as it does in the US, for example. Therefore the first objectives of the thesis at hand are:

*(1.) to adapt and validate a commonly used measure of functional health literacy into four different languages*

*(2.) in order to test its underlying construct and potential relationships in populations outside of the US.*

Part I will report on two studies, which aimed at validating the Short Test of Functional Health Literacy (S-TOFHLA) (Baker et al., 1999) in Switzerland across three language regions, as well as in the PR China. Even though some attempts have been made to develop health literacy tests in these two regions and respective languages (Abel, Hofmann, Ackermann, Bucher, & Sakarya, 2014; Chang, Hsieh, & Liu, 2012; Rau, Sakarya, & Abel, 2014; Wang, Thombs, & Schmid, 2014), there have been no systematic attempts to translate already existing and widely accepted measurement tools into German, French, Italian or simplified Chinese. The aim of these two studies is not only to provide an overview over methodological challenges regarding the translation and adaptation process but also to provide evidence in how far health literacy is correlated with and explained by factors that have proven to be shown to be related to health literacy in the US and, if available, in other countries.

The potential successful adaptation and validation of health literacy measures outside of the US might provide evidence that indeed some of its underlying constructs seem to be transferable to contexts outside of the US. Therefore in a second step this dissertation aims at:

*(3.) understanding whether similar relationships between health literacy and outcomes to those found in the US are detectable elsewhere.*

Part II will provide evidence from two studies that have been conducted in Switzerland. Focus of these studies was to test a potential relationship between health literacy and healthcare costs in a sample of diabetes patients. Given the comparable well-established relationship between health literacy and health outcomes in diabetes patients in the US (Bailey et al., 2014) and the persistent scarcity of research on health literacy in chronically ill patients in Europe, the two studies concentrated on this particular population. Participants in these studies were insured with one of the biggest health insurers in Switzerland, which allowed assessing the relationship of health literacy with accumulated costs.

Results of the two studies are not only relevant to the European context but also provide new evidence to a still understudied relationship in the field of health literacy in general. Even though some evidence has been found that limited health literacy is indeed related to increased costs, the evidence is still far from being conclusive (Howard, Gazmararian, & Parker, 2005; Weiss & Palmer, 2004). Further, results might provide additional confirmation on the potential transferability of the construct of health literacy to other contexts.

Given this traditional take on health literacy, which is aiming at confirmation of transferability and potential applicability of health literacy outside of the US, the last part of this dissertation aims at adding a new conceptual and empirical component to the current discussion on health literacy. Part III of this work will outline two conceptual contributions to the field and one empirical study that aim at:

*(4.) improving our understanding of the potential relationship between health literacy and health disparities.*

Even though it is widely accepted that in particular racial and ethnic minorities are particularly afflicted by the negative outcomes of health disparities, there is still relatively little known about the exact role of health literacy in creating these disparities. A number of attempts have been made to explore how health literacy contributes to it but evidence remains rather incidental (Paasche-Orlow & Wolf, 2010). The ongoing debate on the

conceptualization and definition of health literacy might have prevented it to be more systematically integrated into research on health disparities. Further, the close interrelation of health literacy with other antecedents of health disparities might have made it difficult to coherently integrate and eventually disentangle it from any other concepts in order to understand how it might contribute to disparities in health.

To discuss these possible issues, a collaborative work of different researchers working in the field of health literacy and disparities will be presented. It outlines the current challenges and contradictions that researchers are facing when investigating the link between health literacy and health disparities and provides pointers on how to potentially operationalize these challenges. The second part will outline the current knowledge on health literacy and disparities, by providing a systematic review on empirical studies that have so far investigated the relationship between health literacy and health disparities. The last part is an empirical study that will present findings on the relationship between health literacy and health status in three different immigrant populations in Switzerland, as well as evidence on the effects of differential forms of health literacy on health status.

Results of these three papers will provide some evidence on the last aim of the dissertation at hand:

*(5.) to understand in how far health literacy accounts for unknown variance in health disparities.*

The final chapter of this dissertation will consist of a general conclusion by summarizing the most important findings of the presented studies. It will briefly discuss its results and potential implications for ongoing research on health literacy, specifically its conceptualization and theoretical understanding. In addition, it will discuss future research ideas that are aimed at understanding the interplay between social determinants, health literacy and dynamic environmental processes. In particular, in how far individual health literacy, when conceptualized as a potential outcome of one`s social environment, might influence health information access and sharing. Thus, providing directions on

how to conceptualize and scrutinize health literacy under the assumption that different groups are differently affected by it, potentially leading to disparities in health.

## **Part I**

### **Validation & Adaptation of Health Literacy Measures**

## Chapter 2

### **Functional Health Literacy in Switzerland** *Validation of a German, Italian, and French Health Literacy Test*

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*Abstract*

This study aimed to translate and validate German, Italian, and French versions of the Short-Test of Functional Health Literacy (S-TOFHLA), to be used in Switzerland and its neighboring countries.

The original English version of the S-TOFHLA was translated by applying standardized translation methods and cultural adaptations. 659 interviews were conducted with Swiss residents in their preferred language (249 German, 273 Italian, and 137 French). To assess the validity of the measures, known predictors for health literacy (age, education, and presence of a chronic condition) were tested.

For all three language versions, results show that younger participants, participants with a higher education and participants with chronic medical conditions had significantly higher levels of health literacy. Furthermore, the three health literacy scales categorized participants into three health literacy levels with most people possessing either inadequate or adequate levels. The highest levels of health literacy were found in the Swiss-German sample (93%), followed by the Swiss-French (83%) and Swiss-Italian (67%) samples.

The German, Italian, and French versions of the S-TOFHLA provide valid measures of functional health literacy.

The translated versions can be used in the three different language regions of Switzerland as well as in neighboring countries following ‘country specific’ adjustments and validations.

*Keywords*

Functional health literacy; Validation; German; French; Italian

## 2.1 Introduction

Numerous studies have shown that health literacy is related to people's health outcomes, health status, and their health-related behaviors (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Nielsen-Bohlman, Panzer, & Kindig, 2004; Parker, 2000).

Several instruments are available to measure people's health literacy: the Test of Functional Health Literacy (TOFHLA) (Parker, Baker, Williams, & Nurss, 1995) the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993), and the Short Test of Functional Health Literacy (S- TOFHLA) (Baker, Williams, Parker, Gazmararian, & Nurss, 1999).

The TOFHLA and the REALM represent two fundamentally different approaches to measure health literacy. The TOFHLA is intended to measure patients' ability to read and understand the things commonly encountered in healthcare settings (Parker et al., 1995) and uses the cloze procedure, which requires participants to replace missing words in a given text. The REALM measures one's ability to read and correctly pronounce a list of medical words (Davis et al., 1993). The TOFHLA has been found to be an effective tool for identifying people with inadequate functional health literacy, however it takes up to 22 min to conduct (Baker et al., 1999). For a quicker evaluation of people's health literacy the S-TOFHLA was developed, consisting of two prose passages with a total of 36 cloze items and four numeracy items. The total time to conduct the S-TOFHLA is 12 min or less (Baker et al., 1999).

Numerous studies have employed the S-TOFHLA to identify predictors of health literacy. Inadequate health literacy is most prevalent among those reporting poor overall health (Speros, 2005). Furthermore, older people (Aguirre, Ebrahim, & Shea, 2005; Baker, Gazmararian, Sudano, & Patterson, 2000; Barber et al., 2009; Downey & Zun, 2008; Ginde, Weiner, Pallin, & Camargo, 2008; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005; Williams et al., 1995), men (Parikh, Parker, Nurss, Baker, & Williams, 1996), people with a lower level of education (Aguirre et al, 2005; Brice et al, 2008; Downey & Zun, 2008; Endres, Kaney, Sharp, & Dooley, 2004; Ginde et al, 2008; Jeppesen, Coyle, & Miser, 2009; Ohl et al., 2010) showed lower levels of functional health literacy. Lower levels of health literacy resulted in lower knowledge

about chronic disease (Gazmararian et al, 2006). Variables, which have been shown to predict higher health literacy levels are: the presence of a chronic condition (Jovic-Vranes, Bjegovic-Mikanovic, & Marinkovic, 2009), income (Ginde et al, 2008; Jovic-Vranes et al., 2009; Pizur-Barnekow, Doering, Cashin, Patrick, & Rhyner, 2010; von Wagner, Knight, Steptoe, & Wardle, 2007) and perception of one's own health status (Jovic-Vranes et al., 2009).

### **2.1.1 Review of validation studies**

Currently, validated S-TOFHLAs only exist in a limited number of languages. It has been translated and validated into Spanish (Baker et al., 1999), Brazilian Portuguese (Carthery-Goulart et al., 2009), Hebrew (Baron-Epel, Balin, Daniely, & Eidelman, 2007), Serbian (Jovic-Vranes et al., 2009), Chinese (Cantonese) (Tang, Pang, Chan, Yeung, & Yeung, 2007), and Mandarin (Tsai, Lee, Tsai, & Kuo, 2010).

Carthery-Goulart et al. (2009) translated the S-TOFHLA into Portuguese and adapted it to the Brazilian context to convey information about the Brazilian health system. This required contextual and structural adaptations. However, whenever a sentence needed to be modified due to differences between English and Portuguese, the authors tried to keep the original structure by using alternative stimuli which were either phonetically similar to the original or they used a target belonging to the same grammatical class as the original.

Baron-Epel et al. (2007) translated the S-TOFHLA into Hebrew, but due to differences in the basic structure of English and Hebrew, this could not be done verbatim. Several items required alteration for valid testing in Hebrew and/or needed to be adapted regarding the Israeli health system.

Jovic-Vranes et al. (2009) constructed a Serbian version of the S- TOFHLA, which is conceptually very close to the original English version. The authors translated the English version directly into Serbian using cross-cultural translation techniques, including back translation and semantic adaptations (Sperber, Devellis, & Boehlecke, 1994). Nevertheless, the authors also had to further adapt the questions regarding the Serbian healthcare system. These three studies show that simple word-for-word

translations are not possible and that adaptations have to be employed.

Attempts have also been made to translate and validate the S- TOFHLA into Chinese (Cantonese) (Tang et al., 2007), Mandarin (Tsai et al., 2010), and Korean (Han, Kim, Kim, & Kim, 2011). However, no word-for-word translation was possible and the reading comprehension sections had to be rewritten. Valid health literacy measures were developed for Cantonese (Tang et al., 2007) and Mandarin (Tsai et al., 2010) but not for Korean (Han et al., 2011).

The validation studies provided evidence on the antecedents of health literacy. A lower educational level (Jovic-Vranes, 2009; Baron-Epel et al., 2007; von Wagner et al., 2007), higher age (Jovic-Vranes, 2009; Baron-Epel et al., 2007; von Wagner et al., 2007), being unmarried, unemployment (Jovic-Vranes et al., 2009), low income (Jovic-Vranes et al., 2009; von Wagner et al., 2007) and the absence of chronic conditions (Jovic-Vranes et al., 2009) all correlated negatively with health literacy. Inconsistent results have been found for gender with both men (Baron-Epel et al., 2007), and women (Parikh et al., 1996; von Wagner et al., 2007) possessing higher health literacy levels.

### **2.1.2 Rationale of the study**

To the best of our knowledge no validated S-TOFHLA exists in German, Italian, or French. The aim of the present study was to validate versions of the S-TOFHLA in the three major languages spoken in Switzerland; German, French and Italian since the healthcare system operates in all three languages. Therefore, the present study seeks to evaluate health literacy among Swiss residents in all three language regions and its association with socio-demographic variables and the presence of chronic conditions. As a result, the translated S-TOFHLA versions could not only be employed in Switzerland but also in the neighboring countries Germany, Austria, Italy and France with minimal modifications regarding the national health care systems.

## **2.2 Methods**

### **2.2.1 Participants**

Data collection for the present study took place between June and August 2011 in the

German-, French-, and Italian-speaking regions of Switzerland. Therefore, self-administered paper–pencil questionnaires were distributed within face-to-face interviews at random places such as supermarkets, petrol stations, shopping malls, and public spaces. Participants were chosen according to predefined quota for gender, education, age, and residence. All participants had to be 18 years or older, speak one of the national languages and be Swiss residents.

In total, 659 people participated in the study; all demographic characteristics can be found in Table 1.

Compared with the census data of Switzerland analyzed separately for each language region, participants older than 64 years were underrepresented and participants younger than 64 years were overrepresented in the German- and French-speaking samples but not in the Italian-speaking sample (BFS, 2008). Furthermore, the achieved educational level was slightly higher for achieving a university degree than the respective regional average (BFS, 2008). In contrast, participants who had achieved high-school (University entrance degree) or had finished an apprenticeship were underrepresented in all three language regions (BFS, 2008).

### **2.2.2 Modification and translation of the S-TOFHLA**

The original English S-TOFHLA (Baker et al., 1999) was translated by native speakers of German, Italian, and French into the respective languages following the standard methodologies for questionnaire translation (Sperber et al., 1994). Following translation, the questionnaire was back translated by a native English speaker who was fluent in the respective language to see whether differences between the original English and the translated versions would occur. Back translations were systematically reviewed in accordance with predefined grammatical criteria, which had been formulated when translating the original questionnaire into the three target languages, respectively. Furthermore, special attention was paid to the cultural adaptation of the context. The aim was to provide a translation as close as possible to the original S-TOFHLA to make comparisons between countries possible. However, some minor changes were implemented due to differences in the Swiss Health Care System. Similarly to the

original English version, all three translated versions of the S-TOFHLA consisted of three parts; two prose passages with a total of 36 cloze items and 1 numeracy section consisting of 4 numeracy items (Baker et al., 1999).

### **2.2.3 Interview procedure**

Face-to-face interviews were conducted in all three language regions. At the beginning of each interview the interviewer introduced himself or herself and asked the respondents for their consent. It was also stated that all data are treated confidentially and that it would not be possible to identify respondents according to the answers provided. The first part of the questionnaire consisted of 7 min self-administered cloze questions. Respondents were not informed about the time constraint but were stopped after 7 min by the interviewer stating that sufficient information was gained for the aim of the study. Since the health care services in Switzerland have to provide information in all three languages, participants were allowed to choose their preferred language, as they can when they enter the health care system. The numeracy section was conducted by the interviewer. The whole interview procedure was kept similar to Baker's (1999) except that participants in the present study were not patients.

### **2.2.4 Measurement and analysis**

The scoring system for the health literacy and numeracy measures was based on the scoring system provided by Baker et al. (1999). Each correct answer was scored with one point and each incorrect answer was scored with zero points. Afterwards two summative indices were built for each participant; health literacy ranging from 0 to 36 and numeracy ranging from 0 to 4. According to suggestions in the literature, health literacy was divided into three classes; inadequate (0–16), marginal (17–22) and adequate (23–36) health literacy (Table 2). In order to test the validity of the health literacy measures, known predictors of health literacy such as health status, presence of a chronic condition and other socio-demographic variables were also assessed.

All data were analyzed using SPSS (version 19) and parametric procedures were applied.

## 2.3 Results

### 2.3.1 Reading comprehension and numeracy scores

For all three languages the S-TOFHLA showed good internal consistency. For the reading comprehension sections Cronbach's  $\alpha$  was .73 for the German version, .88 for the Italian version, and .61 for the French version. The numeracy section showed good internal consistency for the Italian version (Cronbach's  $\alpha = .62$ ) and for the French version (Cronbach's  $\alpha = .80$ ) but not for the German version (Cronbach's  $\alpha = .33$ ).

	German	Italian	French
Number of interviews	249	273	137
Mean age (years)	36 (SD = 16.3)	47 (SD = 20.1)	37 (SD = 16.3)
Gender			
Male (%)	47% (N = 117)	48% (N = 132)	55% (N = 61)
Female (%)	53% (N = 132)	52% (N = 141)	45% (N = 75)
Education			
University degree (%)	22% (N = 55)	23% (N = 64)	28% (N = 38)
Vocational school/high school (%)	29% (N = 73)	32% (N = 87)	24% (N = 33)
Secondary school/apprenticeship (%)	43% (N = 107)	37% (N = 102)	42% (N = 58)
No education/primary school (%)	4% (N = 11)	6% (N = 15)	2% (N = 3)

**Table 1: Socio-demographic characteristics of the sample.**

Table 2 shows the distribution of participants' health literacy levels and Table 3 shows the distribution of participants' numeracy levels. The results show that the largest share of people with an inadequate level of health literacy occurred among the Italian-speaking participants, followed by the French-speaking participants. Only a very small proportion of German-speaking participants (3.6%) showed inadequate levels of health literacy. In contrast, the largest share of people with an adequate level of health literacy occurred among the German-speaking participants, followed by the French-speaking participants. The Italian-speaking participants were the group with the smallest number of people possessing adequate health literacy. Moreover, Swiss Italians showed the greatest variety of health literacy levels whereas Swiss Germans were mostly adequately health literate. Additionally, correlations between the reading comprehension score and numeracy score were computed. Results show that for the Italian and French version the correlations were rather high ( $r = .626$ ,  $p < .001$  for the Italian version, and  $r = .493$ ,

$p < .001$  for the French version) but moderate for the German version ( $r = .229$ ,  $p < .001$ ).

	German	Italian	French
	<i>N</i>		
Inadequate health literacy (0–16 correct answers)	9 (3.6%)	58 (21.2%)	16 (11.7%)
Marginal health literacy (17–22 correct answers)	7 (2.8%)	33 (12.1%)	7 (5.1%)
Adequate health literacy (23–36 correct answers)	233 (93.6%)	182 (66.7%)	114 (83.2%)

**Table 2: Number of participants answering the reading comprehension passages correctly.**

Correct (%)	German	Italian	French
Numeracy items			
Take medication every 6h	88	81	84
Normal blood sugar	84	81	76
Appointment slip	95	77	89
Take medication on empty stomach	93	88	88
Total number of questions answered correctly (%)			
0	0	2	6
1	1	7	5
2	6	11	8
3	21	21	14
4	72	59	67

**Table 3: Proportion of participants answering the numeracy items correctly.**

### 2.3.2 Association of functional health literacy with socio-demographic variables

Most past studies showed that younger patients possess a higher level of health literacy than older patients (Aguirre, et al., 2005; Baker, et al., 2000; Barber et al., 2009; Downey & Zun, 2008; Ginde et al., 2008; Paasche-Orlow, et al., 2005; Williams et al., 1995). We, therefore, included the association between age and health literacy as a validation criterion. For each questionnaire version three age groups were defined similarly to Baron-Epel et al. (2007): 18–45, 46–65 and >65 years. The mean differences were analyzed using one-way ANOVA, resulting in significantly different reading and comprehension abilities for all three S-TOFHLA versions (Table 4) with younger participants possessing a higher level of health literacy than older participants.

Past studies also showed that more highly educated people possess higher levels of health literacy (Aguirre et al., 2005; Brice et al., 2008; Downey & Zun, 2008; Endres et al., 2004; Ginde et al., 2008; Jeppesen et al., 2009; Ohl et al., 2010). Results of the present study show that this is also true for the German and Italian versions of the S-TOFHLA but not for the French version (Table 4). For the German version, Tukeys’ HSD post hoc tests show that there are no significant differences between people who achieved a university degree and people who achieved high school or having a vocational degree. All other Tukey’s HSD comparisons resulted in significant differences ( $p<.001$ ). For the Italian versions, all Tukeys’ HSD tests resulted in significant differences ( $p<.001$ ). For the French version no significant results were observed.

	German				Italian				French			
	M	SD	F	<i>p</i>	M	SD	F	<i>p</i>	M	SD	F	<i>p</i>
Age groups												
18–45	32	3.2	14.0	<.001	29	6.2	55.1	<.001	30	6.1	3.2	.042
45–65	30	5.4			24	8.5			27	9.8		
>65	26	9.7			17	8.9			26	7.1		
Education												
No education/primary school	25	9.5	15.8	<.001	8	4.9	40.0	<.001	28	9.3	1.14	.335
Secondary school/apprenticeship	29	5.8			22	9.3			28	8.9		
Vocational school/A-levels	32	1.7			26	7.0			29	6.0		
University degree	33	1.7			30	5.0			31	4.9		

**Table 4: Association between age groups, education and health literacy.**

Past research showed that the presence of a chronic condition results in higher levels of functional health literacy (Jovic-Vranes et al., 2009). The results of the present study also show a difference in the levels of functional health literacy between respondents with and without a chronic condition for the German and Italian versions but not for the French version (Table 5).

The association between gender and health literacy has often been described in the literature (Parikh et al., 1996) with contradictory results (Paasche-Orlow et al., 2005; Parikh et al., 1996). Results are shown in Table 5. For all three language versions no significant differences between male and female participants were found.

In a linear regression model age, education, chronic condition and gender explained 20.8% (German), 42.5% (Italian), and 9.1% (French) of the variance in the health literacy levels (Table 6). Age and education remained associated with health literacy, whereas chronic condition is not directly associated with health literacy.

## **2.4 Discussion and conclusions**

### **2.4.1 Discussion**

The TOFHLA is a widely used measurement for functional health literacy. In order to facilitate the investigation of health literacy, a shortened version of the TOFHLA was developed; the S- TOFHLA. This version of the TOFHLA is available in English and Spanish and has also been translated and culturally adapted into Hebrew (Baron-Epel et al., 2007), Serbian (Jovic-Vranes et al., 2009) and Portuguese (Carthery-Goulart et al., 2009). Furthermore, S- TOFHLA versions have been developed for Mandarin Chinese (Tsai et al., 2010), Chinese (Cantonese) (Tang et al., 2007), and Korean (Han et al., 2011). However, so far the number of translations and therefore the practical application of the S-TOFHLA, especially in central Europe, are limited. The aim of the present study was, therefore, to validate a test for functional health literacy in German, Italian, and French; three widely used central European languages. We conducted the present study in Switzerland because German, Italian, and French are the three official languages in which the health care system operates.

Different predictors of functional health literacy are well established and can be used as criteria for validating a translated S-TOFHLA. The literature review of validation studies revealed three main criteria: age, education, and the presence of a chronic condition. However, not all of the three are usually investigated simultaneously. Since contradictory results for the association between gender and health literacy were found gender cannot serve as a validity criterion. Nonetheless, it is investigated along with the three validation criteria.

	German					Italian					French				
	M	SD	t	df	p	M	SD	t	df	p	M	SD	t	df	p
Chronic condition	31	4.1	2.22	239	<.027	25	8.5	3.5	264	<.001	30	6.5	1.2	128	.25
No chronic condition	29	6.1				20	10.0				28	7.7			
Male	30	4.5	1.07	247	.284	23	9.9	1.96	271	.05	28	8.3	.092	134	.360
Female	31	4.4				26	8.5				29	6.7			

**Table 5: Association between chronic condition and health literacy.**

	German			Italian			French		
	Std Beta	t	p	Std Beta	t	p	Std Beta	t	p
Age	-.288	-4.83	<.001	-.459	-9.11	<.001	-.326	-3.74	<.001
Education	.375	6.44	<.001	.366	7.45	<.001	.107	1.27	.208
Chronic condition	-.104	-1.75	.081	.022	0.43	.666	-.043	-0.50	.617
Gender	-.091	-1.56	.119	-.067	-1.43	.155	-.063	-0.73	.464
R2	.208			.425			.091		

**Table 6: Association between health literacy scores, age, education, chronic condition and gender in a linear regression model.**

### *S-TOFHLA scores*

Overall the German-speaking participants were shown to possess higher levels of functional health literacy than their French- and Italian-speaking counterparts. It is possible that this is a result of cultural differences in the doctor–patient relationship with people in the French- and Italian-speaking regions inherently trusting doctors’ decisions regarding treatment and medication whereas the German-speaking participants may be less trusting of such decisions and like to take part in the decision-making process. However, more research is needed to confirm this assumption.

### *Age*

One of the most important validation criteria is the association between health literacy levels and age. Many studies have shown that levels of functional health literacy decrease with increasing age (Barber et al., 2009; Downey et al., 2008; Ginde et al., 2008; Jovic-Vranes et al., 2009; Paasche-Orlow et al., 2005; von Wagner et al., 2007). Our results for all three S-TOFHLA versions concur with these studies. Despite the fact that functional health literacy decreases with age, participants in the oldest age group in both the German and French version still obtained rather high levels of health literacy and answered at least two-thirds of the questions correctly. This result may again be explained by the generally high educational level in these two language regions of Switzerland. Another reason for the high literacy levels in the older population could be the high life expectancy in Switzerland (men: 79 years, women: 84 years (BFS, 2009) indicating a well-functioning healthcare system. Throughout the years older people with health conditions appear to have acquired the necessary knowledge about their condition, which in turn has been shown to increase their health literacy levels and consequently their health condition (Gazmararian et al., 2006). Similar results could also be expected from a German, Austrian, Italian and French sample.

### *Education*

We, furthermore, investigated the association between achieved educational level and health literacy since it has been shown that education is a good predictor for health

literacy (Barber et al., 2009; Buchbinder et al., 2006; Downey et al., 2008; Ginde et al., 2008; Jeppesen et al., 2009; Jovic-Vranes et al., 2009; Ohl et al., 2010; Paasche-Orlow et al., 2005). We also found very strong associations between the achieved educational level and health literacy for the German and the Italian version, but not for the French version. However, the actual numbers obtained from the French version do not differ from the German version but fewer participants were interviewed for the French version, meaning that group differences must be larger to achieve significance levels. Since differences are rather small due to the generally high education level in Switzerland, the results of the French version still conform with the literature, even though they do not reach statistical significance levels. In general our results show that educational achievement is directly correlated with health literacy. Therefore the associations between education and health literacy, as well as age and health literacy support the validity of the translated measures for all three languages.

#### *Chronic condition*

The presence or absence of a chronic condition has been shown to be a good predictor for people's health literacy (Jovic-Vranes et al., 2009). The results of the present study also show differences in health literacy depending on the presence of a chronic condition for the German and the Italian version but not for the French version. It is assumed, however, that people acquire health literacy skills when they have a medical condition by actively participating in treatment and medication. It has been shown that the French-speaking Swiss take a less active role in health decisions and have a more fatalistic attitude towards health (internal data). Since the Swiss-French participate less in medical activities, there is less learning and consequently no difference between those with and without a chronic condition.

#### *Gender*

Mixed results were found when analyzing gender differences. Nonetheless, we also included gender. We did not expect any gender differences as we were investigating a Swiss population sample and not a minority sample, where gender differences have been

shown (Parikh et al., 1996). Our results show no differences in health literacy levels between male and female participants for all three translated versions. These results concur with a review conducted by Paasche-Orlow et al. (2005) showing no differences of functional health literacy between men and women.

#### **2.4.2 Conclusions and limitations**

Results of the present study show that applying standardized translation techniques enable researchers to create valid translations for the S-TOFHLA. However, if cultural differences are not taken into account (e.g. general high education levels, presence of chronic conditions, general health behavior, or national health insurance obligations), the validity and reliability of the test can be marred, as might have happened with both the German and the French version, which partly show low reliabilities of the measures. Furthermore, statistically non-significant results were obtained for the French-speaking participants possibly due to a relatively smaller sample size.

The German and French versions of the S-TOFHLA appear to have been too easy for the sample in both regions especially the numeracy items since there is hardly any variance observed. This measure only distinguishes between people possessing high and very low health literacy. More than 80% of the participants showed high levels of health literacy and only a small number of participants were categorized into the low health literate group. This concurs with the generally high educational level in Switzerland. In order to test sub-groups of the normal population, the S-TOFHLA should be adjusted to specific national characteristics, e.g. a generally high level of education. In contrast, the Italian version shows both validity and high reliability of the measure. Our study may also be biased due to self-selection of participants. It is possible that only people who felt confident or had the time to fill out the questionnaire participated. This also might account for the high literacy levels in the German and French speaking sample population. However, for quick testing or screening of health literacy all three language versions are valid measures for functional health literacy and can be applied in clinical settings in order to quickly assess whether patients are able to understand basic health information.

### **2.4.3 Practice implications**

For further research in the context of health literacy the Italian version is a valid and reliable measure. To obtain more reliable results for the German and French speaking population we suggest that cultural differences between the language regions should be accounted for, and that the S-TOFHLA should be adapted accordingly. This would also enable the usage and further investigation of health literacy in the neighboring countries Austria, Germany and France.

## Chapter 3

### Health Literacy in Mainland China

#### *Validation of a Functional Health Literacy Test in Simplified Chinese*

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*Abstract*

Health literacy tests in the Chinese-speaking parts of the world have been mainly developed in traditional Chinese to be used in Hong Kong or Taiwan. So far no validated tool in simplified Chinese to assess functional health literacy in Mainland China has been developed.

The aim of the study was to validate the simplified Chinese version of the Short Test of Functional Health Literacy in Adults (S-TOFHLA).

The traditional Chinese version was translated into simplified Chinese and 150 interviews in an outpatient department of a public hospital in Mainland China were conducted.

Predictive validity was assessed by known predictors for health literacy and convergent validity by three health literacy screening questions.

The Cronbach's alpha for the reading comprehension part was .94 and .90 for the numeracy items. Participants with lower education and men had significantly lower levels of health literacy. The reading comprehension part was significantly correlated with two of the three health literacy screening questions.

Our results indicate that the simplified Chinese version of the S-TOFHLA is a reliable measure of health literacy to be used in Mainland China.

*Keywords*

Health literacy; S-TOFHLA; Simplified Chinese; Mainland China

### **3.1 Introduction**

Health literacy defined as the “*degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions*” (Nielsen-Bohlman, Panzer, & Kindig, 2004) has become an area of growing research interest around the world. Studies mainly conducted in the United States (US) have shown the influence of health literacy on a number of health outcomes and health-related behaviours (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Nielsen-Bohlman et al., 2004; Parker, 2000). However, so far research in the field of health literacy has been mainly developed in the English-speaking parts of the world, and even though it has also grown in European countries in recent years, research in other parts of the world is still in its infant shoes (Kondilis, Kiriaze, Athanasoulia, & Falagas, 2008).

#### **3.1.1 Health literacy measures in Chinese language**

Mainland China with a population of 1.3 billion citizens has gone through constant social changes in the last decades including a radical privatization of the health care sector (Blumenthal & Hsiao, 2005), demanding people to become increasingly involved in their health care and to make appropriate decisions regarding their own health. This imposes new challenges on people`s health literacy. Attempts have been made to look at the relationship of health literacy and health outcomes in the Chinese-speaking parts of the world. Yet, most of these studies have been conducted in Taiwan or Hong Kong and only few have looked at the relationship of health literacy and health outcomes in Mainland China.

Context and language specific tools to assess health literacy such as the Taiwan Health Literacy Scale (Pan, Su, & Chen, 2010) and the Mandarin Health Literacy Scale in Taiwan (Tsai, Lee, Tsai, & Kuo, 2010) were developed. The development of the first tool was based on the Rapid Estimate of Adult Literacy in Medicine (REALM) which measures one`s ability to pronounce words (Pan et al., 2010). The Mandarin Health Literacy Scale on the other hand was developed through different expert rounds, eventually comprising 50 items. It has a rather long administration time (Tsai et al.,

2010) and thus is considered to be rather impractical in clinical settings (Leung et al., 2013a).

In Hong Kong, Leung and colleagues (Leung et al., 2013a) developed the Health Literacy Scale for Chronic Care. It tests 4 dimensions (remembering, understanding, applying and analysing) concerning the usage of health information and decision making in the health context. Similar to this scale also a Chinese Health Literacy Scale for Diabetes was developed to evaluate health literacy in diabetes patients (Leung, Lou, Cheung, Chan, & Chi, 2013b).

Other tools in Hong Kong were mainly developed in the field of dentistry, among those the Hong Kong Rapid Estimate of Adult Literacy in Dentistry (HKREALD-30) (Wong et al., 2012) and the Hong Kong Oral Health Literacy Assessment Task for paediatric dentistry (Wong et al., 2013).

Most of these tools have not established construct validity with a validated reference measure and so far only few attempts have been made to translate, adapt and validate already existing health literacy measures. The most common tools to assess health literacy have been developed in English to be used in the US and they are often considered to lack cultural sensitivity. It is argued that especially tools that assess functional health literacy cannot take into account the sentence structures of the Chinese language and its written characters (Leung et al., 2013a) and that their focus on pronunciation and comprehension of the English language might not be applicable in other linguistic contexts (Tsai et al., 2010). Still, one study validated successfully the short-form Test of Functional Health Literacy in Adolescents in a sample of high school students in Taiwan (Chang, Hsieh, & Liu 2012). Another study translated the English version of the Short Test of Functional Health Literacy in Adults (S-TOFHLA) into traditional Chinese to investigate the relationship of functional health literacy and diabetes management outcomes of type 2 diabetes patients in Hong Kong (Tang, Pang, Chan, Yeung, & Yeung, 2008).

### **3.1.2 Measuring health literacy in Mainland China**

In the Chinese-speaking population two different written character systems are used while the pronunciation remains the same (apart from differences in dialects). The traditional characters are mainly used in Taiwan and Hong Kong whereas the simplified characters are used in Mainland China.

Up until today health literacy research in Mainland China has been mainly carried out in public health and not in clinical settings (Wang X. et al., 2013). Those studies used health literacy measures that primarily focussed on understanding and application of health information without assessing reading or numeracy skills (Wang C. et al., 2013). Measures were developed without using established reference measures to assess construct validity. Further, instruments were rather content specific and evaluated mainly knowledge on specific health behaviours or diseases.

In 2009 the Chinese government conducted a study to investigate health literacy in the general population. A measurement tool that consisted of 66 items was developed which looked at different dimensions, such as basic knowledge and beliefs, and healthy lifestyle. The study showed that out of 79'542 participants only 6.48% had adequate literacy (Wang C. et al., 2013). Based on this survey other studies have been conducted looking at the relationship of health literacy and related risk factors (Wang X. et al., 2013) or health status in an elderly minority group (Li, Lee, Shin, & Li, 2009).

Other studies using self-designed health literacy scales investigated the relationship between health literacy and health education in elementary and middle schools (Yu, Yang, Wang, & Zhang, 2012) infectious diseases (Wu et al., 2012; Zhang et al., 2012) and ethnic disparities in health-related quality (Wang C. et al., 2013).

The attempts by the government to assess health literacy in the general public and a growing research body on health literacy in in the country underlines the need for a more systematic approach to develop and validate health literacy measures in simplified Chinese to be used in Mainland China.

### 3.1.3 Objective of the study

So far no established health literacy measure has been translated and validated into simplified Chinese. This includes, besides the validation of functional health literacy measurement tools, also the validation of subjective health literacy screening tools, such as the widely used health literacy screening questions developed by Chew and colleagues (Chew et al., 2008). Thus, the aim of this study was to adapt and validate the Short Test of Functional Health Literacy in Adults (S-TOFHLA) (Baker, Williams, Parker, Gazmararian, A., & Nurss, 1999) in simplified Chinese to be used in Mainland China. Even though the S-TOFHLA has been translated into traditional Chinese to be used in Hong Kong (Tang et al., 2008), no simplified Chinese version of the S-TOFHLA exists. Since in Hong Kong and Taiwan the official writing system uses traditional Chinese characters, the test is not applicable to Mainland China where the standard writing form is simplified Chinese.

The S-TOFHLA is a self-administered paper-pencil questionnaire that measures one's ability to read and understand health related information. It was developed based on a longer version that initially took up to 22 minutes to be completed. The shorter version allows a quicker assessment with a total time of 12 minutes or less to administer. It consists of 36 cloze items, divided into two reading comprehension passages, and four numeracy items (Baker et al., 1999).

Studies have tested the association between a number of potential predictors of health literacy and performance on the S-TOFHLA and have shown that higher age (Baker, Gazmararian, Sudano, & Patterson, 2000; von Wagner, Knight, Steptoe, & Wardle, 2007), as well as lower educational attainment (Aguirre, Ebrahim, & Shea, 2005; Gazmararian et al., 1999), lower levels of income (von Wagner et al., 2007), presence of a chronic condition (Baker et al., 2000) and being unemployed (Pandit et al., 2009) predicted lower levels of functional health literacy.

Evidence on the role of gender is still mixed. Some results point towards the fact that men score higher on health literacy (Olives, Patel, Patel, Hottinger, & Miner, 2011), whereas other studies found that women are more likely to score higher (Aguirre et al.,

2005; von Wagner et al., 2007) and other studies did not find any significant relationship (Gazmararian et al., 1999).

The S-TOFHLA has been translated and validated in a number of languages, such as Portuguese (Carthery-Goulart et al., 2009), Turkish (Eyüboğlu & Schulz, 2015), Serbian (Jović-Vraneš, Bjegović-Mikanović, & Marinković, 2009) or German, French and Italian (Connor, Mantwill, & Schulz, 2013). Those studies largely confirmed the relationships described above.

The three health literacy screening questions developed by Chew and colleagues (Chew, Bradley, & Boyko, 2004; Chew et al., 2008) ask about one's ability to read and understand health related information. They are brief and easy to administer questions that, each separately, are able to detect limited health literacy. Originally developed in a sample of VA patients (Chew et al., 2004; 2008), they have been used across a variety of other contexts and have been shown to correlate with other health literacy measures such as the S-TOFHLA or the REALM (Haun, Luther, Dodd, & Donaldson, 2012).

## **3.2 Methods**

### **3.2.1 Adaptation of the S-TOFHLA**

The authors of the traditional Chinese version of the S-TOFHLA were contacted and asked for permission to translate the test into simplified Chinese to be tested in Mainland China (Tang et al., 2008). A native Mandarin speaker translated the traditional Chinese version into simplified Chinese and minimal changes regarding some expressions were made to make it more applicable to the Chinese health care context.

In order to test for convergent validity the three screening questions for limited health literacy were also translated into simplified Chinese. Also here special attention was paid to cultural and contextual differences but the primary aim was to keep the wording of the questions as close as possible to the originals.

Translations were subsequently reviewed by three native Chinese speakers of whom two were medical doctors.

### **3.2.2 Sample**

Data collection took place between April and May 2013 in an outpatient department of a public hospital in Shaodong county, a rural area in Hunan province, China.

Participants were randomly chosen and had to be 18 years and older, speak Mandarin and be Chinese citizens. Patients who were too ill to participate, had severely impaired sight or were suffering from mental disorders were excluded. In total, 150 patients (50% women) participated in the study.

Trained interviewers approached patients waiting for admittance to the hospital. The purpose of the survey was explained and participants were able to give informed oral consent. Before the beginning of the interview participants were asked to fill in their socio-demographic information. Where necessary, interviewers helped to fill in the information.

The first part of the interview consisted of the health literacy screening questions. In the second part, participants filled in the reading comprehension part, which consists of two passages. Participants were made aware of the fact that this part was timed and would be stopped after seven minutes. Once the seven minutes had passed participants were asked to stop and to continue with the numeracy items.

### **3.2.3 Analyses**

Scores were calculated based on the scoring system provided by Baker and colleagues (1999). In the reading comprehension part every correct answer is scored with 2 points and every incorrect answer with 0 points. The total score of this part is 72 points. The numeracy part totals 28 points. Each correct answer scores 7 points. The total score of the test is 100 points. Inadequate health literacy ranges from 0 to 53 points, marginal between 54 and 66 points and adequate health literacy ranges between 67 and 100 points.

Some other studies have used the scoring system from 0-36 as proposed for testing in clinical settings which scores each correct answer with one point (Jović-Vraneš, Bjegović-Mikanović, Marinković, & Vuković, 2013). Since this scoring system excludes the numeracy items it was decided to stick to the original scoring.

Internal consistency of the 36 items of the prose passage and the 4 numeracy items was assessed by Cronbach's alpha. Spearman's and Pearson's correlation coefficients were calculated to assess the association between known predictors for health literacy, such as educational level, income and age. An independent t-test was conducted to investigate differences in health literacy scores between female and male participants. The association between those variables and health literacy as a continuous variable was further assessed by ANOVA.

To assess convergent validity Pearson's correlation coefficients were calculated to assess the association between the S-TOHLA and the three screening questions. Chew and colleagues (2008) identified in their study that a combination of all three items would not lead to any changes in detecting limited health literacy. Therefore each item was reported separately.

A linear regression model was calculated to estimate the relationship between the socio-demographic predictors and health literacy.

All data were analyzed using SPSS version 21 and parametric procedures were applied. Statistical significance was set at  $p < .05$ .

### **3.3 Results**

#### **3.3.1 Sample characteristics**

Most of the respondents were in the age group 36-55 (38.7%). The number of men and women was equal (50%). 92% of participants were Han, the ethnic majority in China.

10.7% had six years or less of schooling, 19.3% finished secondary school, 28% indicated to have finished high school or vocational training, followed by 29.3% who indicated to have finished junior college and 12.7% having a university degree (Table 7).

Most respondents (50%) indicated to earn 2000 RMB<sup>1</sup> or less.

#### **3.3.2 Reading comprehension part and numeracy items**

The simplified Chinese version of the S-TOFHLA showed good internal consistency. For the 36 Cloze items in the reading comprehension part the Cronbach's alpha was .94

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<sup>1</sup> 1 RMB = 0.16 US-Dollar

and for the four items of the numeracy section .90. The correlation for the numeracy score and the reading comprehension score was .362,  $p < .001$ .

Overall 40.4% of participants showed to have adequate health literacy, followed by 32.9% possessing marginal health literacy and 26.7% possessing inadequate health literacy.

	Number	Health Literacy				
		Mean	S.D.	Inadequate	Marginal	Adequate
Total	150					
Gender						
Male	75	54.69	22.8	27 (35.0%)	28 (37.3%)	20 (26.7%)
Female	75	65.99	21.6	16 (21.3%)	20 (26.7%)	39 (52.0%)
<i>p</i>		.002			.006	
Age						
18-35	52	64.06	20.0	15 (28.8%)	15 (28.8%)	22 (42.3%)
36-55	58	61.69	21.6	14 (24.1%)	19 (32.8%)	25 (43.1%)
56-75	38	53.95	22.5	13 (34.2%)	14 (36.8%)	11 (28.9%)
<i>p</i>		.096			.620	
Education						
Primary School (6 yrs)	16	26.63	25.7	11 (68.8%)	4 (25.0%)	1 (6.3%)
Secondary School (3 yrs)	29	57.72	22.1	12 (41.4%)	9 (31.0%)	8 (27.6%)
Vocational/High School (3 yrs)	42	64.29	18.4	7 (16.7%)	16 (38.1%)	19 (45.2%)
Junior College (3 yrs)	44	69.82	16.6	8 (18.2%)	11 (25.0%)	25 (56.8%)
University (4 yrs and more)	19	62.05	17.4	5 (26.3%)	8 (42.1%)	6 (31.6%)
<i>p</i>		<.0001			.001	

**Table 7: Mean scores and distribution of respondents' level of health literacy by gender, age and education.**

### 3.3.3 Predictive validity

Predictive validity was assessed by the association of socio-demographic variables with the S-TOFHLA scores. Spearman's correlation between education and the overall health literacy score was moderate ( $\rho = .303$ ,  $p < .001$ ). Correlations between the reading comprehension part and education ( $\rho = .256$ ,  $p < .001$ ) and the numeracy part and education ( $\rho = .247$ ,  $p < .001$ ) separately were also moderate.

A one-way ANOVA of the relationship between highest achieved education and the overall S-TOFHLA score was conducted,  $F(4, 145) = 15.247$ ,  $p < .001$ . Tukey's HSD post-hoc test showed significant differences between people who indicated primary

school as highest educational level and all other educational levels. All other comparisons resulted in non-significant differences.

For the reading comprehension part Levene's test indicated that the assumption of homogeneity of variance was violated,  $F(4,145)=9.251$ ,  $p<.001$ . Transforming the data did not correct this problem but Games-Howell post-hoc test revealed the same significant difference between primary school and all other educational levels. All other comparisons resulted in non-significant results.

A significant correlation between age and the overall health literacy score was found ( $r=.136$ ,  $p<.05$ ). No significant correlations between age and the reading comprehension part and age and the numeracy part were found.

Income did not correlate significantly with the overall health literacy score, neither with reading comprehension nor the numeracy part.

An independent t-test was conducted to evaluate differences in gender regarding health literacy levels. The test was significant,  $t(148)=3.113$ ,  $p<.05$ . Female participants ( $M=65.99$ ,  $SD=21.583$ ) showed on average higher health literacy levels than male participants ( $M=54.69$ ,  $SD=22.836$ ). These results showed to be consistent in the reading comprehension and numeracy part separately (Table 7).

### **3.3.4 Convergent validity**

The health literacy screening questions "*How often do you have problems learning about your medical condition because of difficulty understanding written information?*" ( $r=.259$ ,  $p<.001$ ) and "*How often do you have someone help you read hospital materials?*" ( $r=.206$ ,  $p<.05$ ) showed to be significantly correlated with the reading comprehension part. The question "*How confident are you filling out medical forms by yourself?*" did not correlate significantly with any of the other measures. Also, there were no significant correlations found between the three screening questions and the overall S-TOFHLA score or respectively the numeracy items.

### 3.3.5 Regression model

In a linear regression model education, gender and age explained 22% of the variance where education and gender remained associated with health literacy but age not (Table 8).

	Health Literacy		
	Standardized beta	<i>t</i>	<i>p</i>
Education	.408	5.296	<.001
Gender*	.287	3.878	<.001
Age	-.046	-.595	.553
<i>R</i> <sup>2</sup>	.223		

**Table 8: Association between overall health literacy score and education, gender and age in a linear regression model.**

### 3.4 Discussion

To our knowledge this is the first study to validate a functional health literacy measure in Mainland China. So far most of the health literacy measurement tools have been developed and validated in Hong Kong and Taiwan. Since the official written language in Mainland China is simplified Chinese and the health care sector operates in written form in it, it is necessary to develop health literacy measures in simplified Chinese.

Overall the simplified Chinese version of the S-TOFHLA showed to be a reliable measure as indicated by a high Cronbach’s alpha (internal consistency) for both the reading comprehension part and the numeracy items separately. The distribution across the three different health literacy levels was fairly equal, with the majority having adequate health literacy.

Our analysis was based on predictive validity taking into account different predictors for functional health literacy. Established predictors for functional health literacy are age, educational level and income. Results of the study concur with results found in other studies. One important validation criteria is the association between educational level and health literacy (Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005), an association that was also found in the current study and which supports the validity of the tool.

Even though we would have expected that higher income would be predictive of higher health literacy levels, we did not find a significant relationship between income

and health literacy. Yuan and colleagues (2015) found that residents in rural areas of Mainland China with lower income were more knowledgeable about health topics. This warrants a closer investigation in order to identify the underlying mechanisms leading to these rather unexpected relationships.

Even though differences with regard to age and health literacy were not significant, the data shows that older participants scored in average lower on the S-TOFHLA. Further analysis for the screening questions revealed the same pattern.

We did not find any significant differences in education with regard to gender, still gender was an important variable in predicting health literacy in our sample. Female participants in general scored significantly higher, which is in line with results found in the US (Aguirre et al., 2005; von Wagner et al., 2007). Yet, other validation studies have shown different results. In the Turkish and Serbian versions of the S-TOFHLA for example men scored significantly higher (Eyüboğlu & Schulz, 2015; Jović-Vraneš et al., 2009) whereas in the German, French and Italian version no significant differences were found (Connor et al., 2013).

Convergent validity was assessed by correlating the simplified Chinese version of the S-TOFHLA with the translated health literacy screening questions (Chew et al., 2008). Two of the three questions showed to be significantly correlated with the reading comprehension part. These results are not surprising since both questions assess the understanding of written health information.

### **3.4.1 Limitations**

Based on a fairly equal distribution across different health literacy levels, age groups and gender, we can assume that the population in our study was sufficiently diverse to investigate the relationship between commonly-cited predictors of health literacy and performance on the S-TOFHLA. Nevertheless the results cannot be generalized since data was collected in a rural area in China. More research is needed in more urban areas with a more representative sample.

Besides, the number of missing values in the numeracy items and health literacy screening questions was rather high, which deserves further investigation. One possible

explanation with regard to the health literacy screening questions (ca. 30% missing values) might have been the wording or format that might not have been clear to the participants. Even though data was not treated as missing for the numeracy items, further investigation is needed to better understand whether people truly did not know the answer or if also here the format or mode of administration might have been problematic.

### **3.4.2 Conclusion**

The validation of the S-TOFHLA in simplified Chinese has been a first attempt to apply an already existing measure in Mainland China and to establish a reference measure to evaluate health literacy levels in a clinical setting in the Chinese population. Even though some aspects still need further investigation, including testing in a more representative sample, the simplified Chinese version of the S-TOFHLA seems to be a reliable measure to be used in primary care patients in Mainland China.

## **Part II**

### **Health Literacy and Healthcare Costs**

## Chapter 4

### **The Relationship between Functional Health Literacy and the Use of the Health System by Diabetics in Switzerland**

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*Abstract*

Observational studies from the United States have suggested that patients with low health literacy have higher healthcare costs and use an inefficient mix of healthcare services. So far, there were no studies from Europe, which investigated the impact of health literacy (HL) on the use of the health system. The purpose of this study was to measure functional HL among persons having diabetes type 2 and to investigate the relationship between functional HL and health care costs and utilization.

The study population were insured persons of the basic health insurance plan of the largest health insurer in Switzerland. Persons selected for participation had been reimbursed for diabetes medications in the years 2010-2011, were aged between 35-70 and did not live in a long-term care institution. The level of functional HL was measured by one screening question. As dependent variables were used total costs, outpatient costs, inpatient costs, days admitted and number of physician visits attended. All multiple regression analyses were adjusted for age, gender, education, duration of diabetes, treatment with insulin yes/no, other chronic disease yes/no.

High levels of functional HL were associated with lower total costs ( $p=.007$ ), lower outpatient costs ( $p=.004$ ) and less physician visits ( $p=.001$ ). In the standard insurance plan with free access to all health professionals subgroup, the effects found were more pronounced.

Persons with low functional HL need more medical support and therefore have higher health care costs.

*Keywords*

Health literacy; Diabetes mellitus type 2; Healthcare costs

## 4.1 Introduction

The ability of citizens to take care of their own health and to navigate through increasingly complex healthcare systems has been recognized as a significant factor in healthcare costs and quality (Kickbusch, Wait, & Maag, 2005). Thus, health literacy (HL) has become an important research topic. The World Health Organization (WHO) has defined HL as the “*cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health*” (Nutbeam, 1986). Studies have shown that limited HL is associated with poorer health outcomes (Dewalt, Berkman, Sheridan S, Lohr & Pignone, 2004; Mancuso & Rincon, 2006) and lower use of preventive health services (Garbers & Chiasson, 2004; Guerra, Dominguez & Shea, 2005; Howard, Gazmararian & Parker, 2005).

For people suffering from diabetes, HL is even more important, as they have to be able to integrate health-related self-management activities in their daily life such as following medication plans, respecting dietary intake modifications or being able to communicate with healthcare providers (Nolte & McKee, 2008). So far, studies of the relationship between HL and diabetes control have provided mixed results. Some studies found associations between low HL and worse glycaemic control (Schillinger, Barton, Karter, Wang & Adler, 2006; Tang, Pang, Chan, Yeung & Yeung, 2008), more hypoglycaemic events (Sarkar, et al., 2010) and higher rates of retinopathy (Schillinger et al., 2002). Other studies did not confirm a relationship between glycaemic control and HL (Mancuso, 2010; Morris, MacLean & Littenberg, 2006).

However, different studies found associations between low HL and higher total healthcare spending (Hardie, Kyanko, Busch, Losasso & Levin, 2011), higher emergency department use (Baker et al., 2004), and higher inpatient costs (Howard et al, 2005; Berkman., Sheridan, Donahue, Halpern & Crotty, 2011). Eichler et al. (2009) estimated the additional costs on the health system level associated with low HL in the range of 3 to 5% of the total healthcare costs per year. All these studies were based on data from the United States. Considering the important differences between the

European and the US-American living conditions as well as the healthcare systems, these findings cannot be generalized.

In Switzerland for example, basic health care insurance is compulsory for all citizens. They can choose between different insurers and the insurers are obliged to accept every person in the basic healthcare insurance. Independent of the chosen insurer, the basic healthcare insurance covers the same medical costs for diagnostic and therapeutic procedures approved by law. Outpatient costs include all diagnostic and therapeutic procedures prescribed or conducted by approved physicians in the ambulatory setting. Inpatient costs include all diagnostic and therapeutic procedures undertaken in approved hospitals. Co-payment of medical costs by the insured persons consists of a deductible (annual amount paid by insured persons towards the costs of medical benefits) and an excess (percentage of the costs invoiced annually for medical benefits over and above the amount of the deductible, but no more than the maximum amount per year specified by law). Insured persons can choose to pay higher annual deductibles or choose between different alternative insurance options with a restricted choice of service providers in return for reduced premiums.

For our study, we selected patients with diabetes type 2 because diabetes is one of the most common diseases with 366 million people affected worldwide in 2011 (International Diabetes Federation, 2012). In Switzerland, more than 300'000 people are suffering from diabetes with about 15'000 persons newly diagnosed per year (Bestetti, Schönenberger & Koch, 2005). About 2.2% of the country's total healthcare expenditures are spent for the treatment of diabetes and its complications (Schmitt-Koopmann, Schwenkglenks, Spinass & Szucs, 2004). In particular, persons with a low socioeconomic status suffer up to four times more frequently from diabetes than persons with a high socioeconomic status (Häussler & Berger, editors, 2004).

Even though health literacy as a concept has been subject to constant changes and refinements, the development of measurements is still lagging behind (Berkman, Davis & McCormack, 2010). Although most definitions assume that there is more to HL than functional literacy, comprehensive tools that capture this multidimensionality are still lacking (Mancuso, 2009). The Test of Functional Health Literacy (Parker, Baker,

Williams & Nurss, 1995) and the Rapid Estimate of Adult Literacy in Medicine (Davis et al. 1993) are two of the most commonly used measurement tools. Both test functional HL, where the TOFHLA aims at capturing patients reading comprehension and numeracy skills and the REALM word recognition and pronunciation skills.

Another way to measure health literacy are screening questions. Most of these questions ask about one`s ability to understand health-related materials and some have tried to capture the multidimensionality of the concept. Nevertheless lack of external validity poses often a problem and so far none of these measures has been considered to be the gold standard (Frisch, Camerini, Diviani & Schulz, 2012).

The purpose of this study was to measure functional HL among persons having diabetes type 2 and to examine the relationship between HL and healthcare costs and utilization. To the best of our knowledge, this is the first study conducted in Europe combining functional health literacy measurement of patients suffering from diabetes type 2 and the cost outcome data.

## **4.2 Methods**

### **4.2.1 Study population**

The study population were insured persons of the basic health insurance plan of the Helsana Group, the largest health insurer in Switzerland. Persons were eligible for the study if they had been reimbursed for diabetes medications (Anatomical Therapeutic Chemical (ATC) classification system A10A or A10B) in the years 2010 and 2011, were not living in a long-term care institution and were aged between 35 and 70 years.

There are different official languages in the different parts of Switzerland. As health literacy may interfere with knowledge of the language, persons were only eligible if they had chosen the official language within the region where they were living as the correspondence language with the insurance company.

A randomized sample consisting of 7'550 persons in the German-speaking part, 2'926 persons in the French-speaking part and 1'111 persons in the Italian-speaking part of Switzerland was contacted by letter. For enrolment they had to return a consent form

by prepaid envelope to the University of Lugano indicating whether they were suffering from diabetes mellitus type 2.

#### **4.2.2 Interview data**

Participants were interviewed by trained students of the University of Lugano in spring 2012. Telephone interviews were conducted in the three official languages of the regions. Collected data included demographic information, information on health status and functional HL as measured by one screening item (More measures of HL have been included in the original questionnaire but for the purpose of this study it was decided to focus on the measure for functional HL).

Because the TOFHLA or the REALM are not suitable for telephone interviews, we used one of the three screening items developed by Chew et al. (2004; 2008). All three items refer to functional health literacy asking patients about their perceived competence to understand health-related information material. The studies of Chew et al. showed that the item *“How often do you have problems learning about your medical condition because of difficulty understanding written information?”* had an AUROC of 0.76 (95% CI=0.62-0.90) for identifying persons with inadequate HL resp. an AUROC of 0.60 (95% CI=0.51-0.69) for identifying persons with inadequate or marginal HL. The authors indicated in their study that the combination of all 3 items would not lead to any significant change in detecting health literacy levels (Chew et al., 2008). Therefore, we chose only one out of three items as this one was the most applicable to the Swiss healthcare context. As the translation of the original question could be misinterpreted, we used a slightly adapted version: *“When you get written information on a medical treatment or your medical condition, how often do you have problems understanding what it is telling you?”* The study protocol was approved by the appropriate regional ethical committee “Comitato etico cantonale, Ticino”.

#### **4.2.3 Insurance data**

We retrieved all costs and utilization data for the years 2010 – 2011 from the insurer’s administrative database including all co-payments (deductible and excess). We

distinguished three categories of health insurance plans. The standard insurance plan included free access to all physicians, in the telephone counselling plan the insured person had to call a medical call centre before going to a physician and in the gatekeeper-model the insured person had to go first to a selected physician.

#### **4.2.4 Statistical analysis**

We corrected the non-normal distribution of costs and utilization data by using the log transformation. To identify differences between participants and non-participants in health care costs and utilization, we used Levene's test for homogeneity of variance and the independent t-test for equality of means.

Multiple regression analyses were conducted to analyse the relationship between the level of functional HL and healthcare costs and utilization. As dependent variables for healthcare costs we used total costs, outpatient costs and inpatient costs. Based on the data available the utilization of the healthcare system was assessed through the days admitted in hospital and the number of physician visits attended. Levels of health literacy were used as independent dummy variables comparing the different levels of functional HL to the group with the highest level of functional health literacy. All regression models included as covariates age, gender, duration of diabetes, treatment with insulin, other chronic condition and education. To control for influences of the chosen health insurance plan, we performed a subgroup analyses of persons having chosen the standard insurance plan. All statistical analyses were performed with SPSS 19.

### **4.3 Results**

#### **4.3.1 Sample characteristics**

From the 11'587 contacted persons we received 2'075 response cards, 1'097 declined participation and 335 persons did not fulfil the inclusion criteria because they had no diabetes type 2. Of the 588 eligible persons 34 declined later their participation, 57 were not reachable by phone, 2 did not finish the interview and in two cases the interviewed

persons were not the selected persons. Finally, interview data could be obtained from 493 persons (Figure 1).

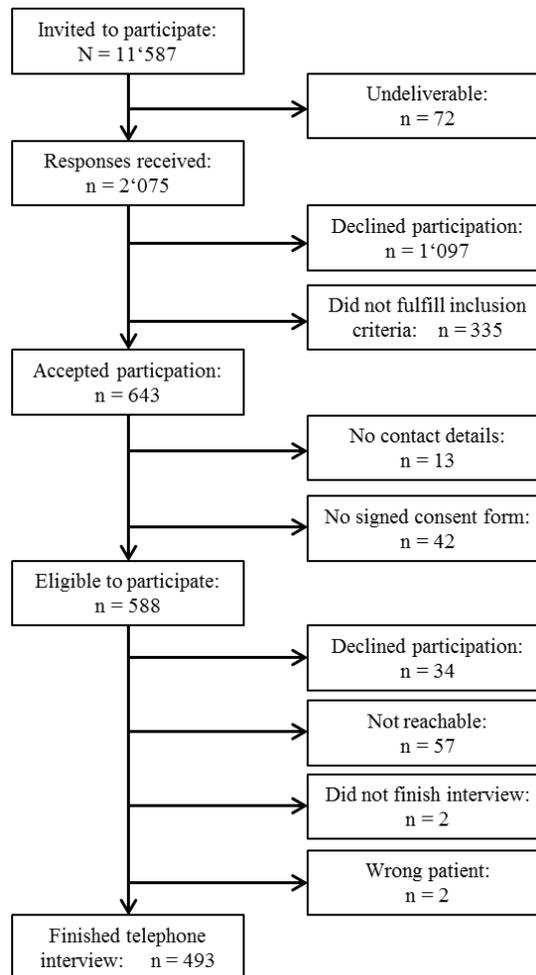


Figure 1: Enrollment process

We found that males, or those aged >65, or those living in the German-speaking region of Switzerland, or those having chosen a higher cost participation or a gatekeeper-model as insurance plan were more likely to participate (Table 9).

Of the 493 participants, 441 (89%) had been diagnosed with diabetes type 2 >5 years ago and 164 participants (33%) were treated with insulin. 227 participants (46%) had other chronic diseases. 12 persons reported having suffered from diabetes for one year or

less, but according to the insurance claims data all participants received medications against diabetes for at least 2 years.

2011	Participants		Non-Participants		Total		$\chi^2$	<i>p</i>
	n	%	n	%	N	%		
<b>Gender</b>								
male	332	67.3	6'690	60.3	7'022	60.6	9.798	.002
female	161	32.7	4'404	39.0	4'565	39.4		
<b>Age</b>								
35 - 44	8	1.6	743	6.7	751	6.5	123.231	<.001
45 - 54	42	8.5	2'258	20.4	2'300	19.8		
55 - 64	189	38.3	4'743	42.8	4'932	42.6		
65 - 70	254	51.5	3'350	30.2	3'604	31.1		
<b>Language</b>								
German	391	79.3	7'159	64.5	7'550	65.2	45.42	<.001
French	74	15.0	2'852	25.7	2'926	25.3		
Italian	28	5.7	1'083	9.8	1'111	9.6		
<b>Annual deductible</b>								
≤ € 250	350	71.0	7'613	68.6	7'963	68.7	11.158	.004
= € 417	105	21.3	2'917	26.3	3'022	26.1		
≥ € 833	38	7.7	564	5.1	602	5.2		
<b>Insurance plan</b>								
Standard	274	55.6	7'738	69.7	8'012	69.1	45.756	<.001
Telephone counselling	58	11.8	992	8.9	1'050	9.1		
Gatekeeper model	161	32.7	2'364	21.3	2'525	21.8		
<b>Total</b>	<b>493</b>	<b>100.0</b>	<b>11'094</b>	<b>100.0</b>	<b>11'587</b>	<b>100.0</b>		

**Table 9: Study population characteristics.**

### 4.3.2 Functional Health literacy

Half of the participants declared never having problems to understand written information related to their medical condition. In contrast, 7.3 % of the participants often or always had problems to understand written information (Table 10).

### 4.3.3 Health care costs and utilization

For healthcare costs and utilization, the Levene's test was in all categories non-significant confirming the homogeneity of variances in participants and non-participants. In the year 2011, participants on average caused significantly higher total costs ( $GM^2 = € 5'155$ ,  $SE=1.05$  vs.  $GM = € 4'393$ ,  $SE=1.01$ ;  $t(11'585)=3.10$ ,  $p=.002$ ), higher

<sup>2</sup>  $GM$ =geometric mean

outpatient costs ( $GM=€4'137$ ,  $SE=1.04$  vs.  $GM=€ 3'669$ ,  $SE=1.01$ ;  $t(11'585) = 3.06$ ,  $p=.002$ ) and more physician visits ( $GM=24$ ,  $SE=1.04$  vs.  $GM=20$ ,  $SE=1.01$ ;  $t(11'199)=5.10$ ,  $p<.001$ ) than non-participants. These differences were confirmed by the data of the year 2010.

*"When you get written information on a medical treatment or your medical condition, how often do you have problems understanding what it is telling you?"*

	n	%
Always	12	2.4
Often	24	4.9
Sometimes	78	15.8
Occasionally	129	26.2
Never	250	50.7
Total	493	100

**Table 10: Results of the HL screening question**

#### 4.3.4 Multiple regression analyses

Multiple regression analyses were conducted to evaluate the association between HL and different health care costs and utilization variables. The results of the regressions suggested that persons with lower levels of HL caused higher total costs, higher outpatient costs and had more physician visits (Table 11). In the subgroup analysis of patients having chosen the standard insurance plan with free access to all health professionals, the effects found were more pronounced (Table 12).

Linking Health Literacy and Health Disparities

Year 2011 (n = 492)								Year 2010 (n = 492)								
Dependent variables	Predictive variable	R <sup>2</sup>	B	SE	Beta	p	95.0% CI for B	Dependent variables	Predictive variable	R <sup>2</sup>	B	SE	Beta	p	95.0% CI for B	
Total costs	Occasionally	.152	-.050	.115	-.020	.663	-.275 .175	Total costs	Occasionally	.152	.068	.113	.027	.549	-.154 .289	
	Sometimes		.104	.138	.034	.449	-.166 .375		Sometimes			.243	.135	.081	.073	-.023 .508
	Often		.342	.225	.066	.130	-.101 .784		Often			.342	.221	.067	.123	-.093 .777
	Always		.849	.312	.118	<b>.007</b>	.236 1.463		Always			.626	.307	.088	<b>.042</b>	.023 1.228
Outpatient costs	Occasionally	.226	-.078	.086	-.039	.362	-.247 .091	Outpatient costs	Occasionally	.176	.020	.088	.010	.816	-.152 .193	
	Sometimes		.038	.103	.016	.715	-.165 .241		Sometimes			.109	.106	.046	.304	-.099 .316
	Often		.256	.169	.063	.130	-.076 .588		Often			.256	.173	.064	.139	-.083 .596
	Always		.673	.234	.119	<b>.004</b>	.213 1.133		Always			.544	.240	.097	<b>.024</b>	.073 1.015
Inpatient costs	Occasionally	.149	.100	.223	.049	.656	-.342 .541	Inpatient costs	Occasionally	.148	.233	.241	.108	.336	-.246 .712	
	Sometimes		.158	.281	.064	.574	-.399 .715		Sometimes			.072	.275	.031	.794	-.475 .619
	Often		.754	.419	.186	.075	-.077 1.585		Often			.766	.443	.187	.087	-.114 1.647
	Always		.466	.425	.115	.276	-.378 1.310		Always			.152	.487	.034	.756	-.817 1.120
Days admitted	Occasionally	.094	.025	.257	.011	.921	-.485 .535	Days admitted	Occasionally	.192	.291	.256	.127	.258	-.217 .799	
	Sometimes		-.051	.324	-.018	.875	-.694 .592		Sometimes			.130	.298	.051	.664	-.463 .723
	Often		.177	.483	.039	.715	-.782 1.136		Often			1.025	.471	.236	.032	.089 1.961
	Always		.655	.490	.145	.185	-.318 1.629		Always			.311	.514	.065	.547	-.711 1.332
Physician visits	Occasionally	.088	-.072	.084	-.040	.394	-.237 .093	Physician visits	Occasionally	.090	.043	.083	.024	.609	-.121 .206	
	Sometimes		.179	.100	.084	.075	-.018 .377		Sometimes			.234	.100	.111	<b>.019</b>	.038 .430
	Often		.123	.164	.034	.454	-.200 .446		Often			.273	.163	.076	.094	-.047 .593
	Always		.786	.228	.156	<b>.001</b>	.339 1.234		Always			.751	.225	.150	<b>.001</b>	.308 1.194

**Table 11: Regression coefficients quantifying associations between HL screening question and health care costs and utilization.**

*Note: all regressions included as covariates age, gender, education, duration of diabetes, treatment with insulin yes/no, other chronic disease yes/no.*

Linking Health Literacy and Health Disparities

Year 2011 (n = 274)									Year 2010 (n = 292)									
Dependent variables	Predictive variable	R <sup>2</sup>	B	SE	Beta	p	95.0% CI for B		Dependent variables	Predictive variable	R <sup>2</sup>	B	SE	Beta	p	95.0% CI for B		
Total costs	Occasionally	.200	.085	.151	.034	.574	-.213	.382	Total costs	Occasionally	.174	.179	.150	.070	.234	-.117	.475	
	Sometimes		.272	.184	.088	.142	-.091	.634		Sometimes			.152	.176	.050	.388	-.195	.499
	Often		.664	.297	.130	<b>.026</b>	.080	1.248		Often			.342	.266	.074	.199	-.181	.864
	Always		1.483	.424	.200	<b>.001</b>	.648	2.319		Always			1.260	.430	.165	<b>.004</b>	.414	2.105
Outpatient costs	Occasionally	.276	-.004	.113	-.002	.971	-.226	.218	Outpatient costs	Occasionally	.191	.064	.116	.032	.583	-.164	.291	
	Sometimes		.120	.138	.049	.383	-.151	.391		Sometimes			-.008	.136	-.003	.956	-.274	.259
	Often		.342	.222	.085	.124	-.095	.778		Often			.317	.204	.088	.122	-.085	.719
	Always		1.219	.317	.210	<b>.000</b>	.595	1.843		Always			1.073	.331	.181	<b>.001</b>	.422	1.723
Inpatient costs	Occasionally	.233	.147	.273	.072	.591	-.399	.693	Inpatient costs	Occasionally	.345	.457	.283	.208	.113	-.111	1.025	
	Sometimes		.139	.330	.059	.675	-.522	.800		Sometimes			-.319	.343	-.130	.356	-1.007	.368
	Often		.907	.462	.251	.054	-.018	1.831		Often			1.053	.596	.223	.083	-.144	2.250
	Always		.262	.473	.073	.582	-.684	1.208		Always			.269	.546	.065	.625	-.827	1.364
Days admitted	Occasionally	.162	.069	.312	.031	.826	-.556	.694	Days admitted	Occasionally	.281	.467	.340	.193	.177	-.217	1.151	
	Sometimes		-.241	.378	-.093	.526	-.998	.516		Sometimes			-.135	.415	-.048	.746	-.969	.698
	Often		.077	.529	.019	.885	-.982	1.135		Often			1.193	.709	.231	.098	-.230	2.617
	Always		.327	.541	.083	.547	-.755	1.410		Always			.426	.648	.095	.514	-.877	1.729
Physician visits	Occasionally	.143	-.061	.117	-.032	.606	-.292	.171	Physician visits	Occasionally	.116	.049	.111	.027	.657	-.169	.267	
	Sometimes		.301	.142	.131	<b>.035</b>	.021	.581		Sometimes			.211	.129	.099	.103	-.043	.464
	Often		-.047	.229	-.012	.838	-.497	.403		Often			.238	.194	.073	.222	-.145	.620
	Always		1.202	.327	.220	<b>.000</b>	.559	1.846		Always			1.206	.314	.226	<b>.000</b>	.588	1.825

**Table 12: Regression coefficients of the subgroup analysis "Standard insurance plan" quantifying associations between HL screening question and health care costs and utilization.**  
*Note: all regressions included as covariates age, gender, education, duration of diabetes, treatment with insulin yes/no, other chronic disease yes/no.*

#### 4.4 Discussion

The study demonstrated that patients with diabetes type 2 with low functional HL had higher total and outpatient costs. This is also reflected in the fact that patients with lower HL levels saw their physicians more frequently than patients with higher levels of HL, as visiting the physician is reflected in both total and outpatient costs. Functional HL was operationalized by self-reported competence to understand written information about their medical condition.

Some further observations substantiate this finding. The inpatient costs and the days admitted to a hospital also tended to be higher in low-HL patients, but the difference did not reach a significant level. Nevertheless, the fact that with each decreasing level of HL the association became stronger (increasing regression betas) further supports the general finding. Improving the evidence beyond what other studies show, we were able to demonstrate that the negative relationship between levels of functional HL and health care costs and health system utilization was stable over 2 years.

Our findings of a relationship between HL and outpatient costs and the number of physician visits are in contrast to studies conducted in the United States, where office visit rates were shown to be similar across the range of health literacy scores (Hardie et al., 2011). Further, studies from the U.S. showed that lower HL was associated with higher emergency department as well as higher inpatient admission costs (Hardie et al., 2011; Howard et al., 2005), thereby suggesting that low-HL patients there may use an inefficient mix of health services. Our results do not suggest something similar for Switzerland. One explanation could be the general low number of hospital days in our sample. Another explanation could be that, in contrast to the U.S., the fast and easy access to physicians in private practices in Switzerland diminishes the number of hospital admissions and inpatient costs. This would also explain the greater effect we found on the physician visits and the outpatient costs. That people with low HL visit their physician more often can also be traced back to their worse glycaemic control and/or more comorbidities and the higher need for medical support caused by this.

In the subgroup of persons having chosen the standard insurance plan without telephone counselling or a gatekeeper, the effects were even more pronounced. This

might be due to the fact that persons with low HL would need these services more, and not having them, their insecurity in the choice of the appropriate healthcare provider results in navigating through turning to the health care system more frequently.

Our sample showed a low variance of HL levels, which made it more difficult to discern significant differences. Most studies identified at least 20% of patients with low HL (Berkman et al., 2011). In our sample only 7.3% were considered to have inadequate HL. But according to the Adult Literacy and Life Skills Survey (Notter, Arnold, von Erlach & Hertig, 2006) at least 40 % of the Swiss population do have low levels of general problem-solving, literacy and numeracy skills. As HL is correlated with education, we assume that persons with low HL were underrepresented in our sample due to participation bias. Despite this constraint, the association between low HL and healthcare costs and utilization remained significant. The likely underrepresentation of persons with low HL makes us conclude that our study underestimates the true effect of low HL on healthcare costs and health care system utilization in Switzerland.

There are several limitations to this study. First, as most of the participants showed a high level of HL, it is possible that the chosen item for its measurement was not sufficiently accurate. More established instruments, such as the S-TOFHLA or the REALM, however, could not be used for telephone interviews. The next best choice was a validated item from Chew et al. (2004; 2008).

Second, although the presence of another chronic disease was integrated as a covariate in all regression models, we had no medical data to confirm the self-reported comorbidities. Low HL could result in underreporting comorbidities and therefore lead to overestimation of the effect of low HL on healthcare costs and use. On the other hand, more comorbidities could mediate the relationship between low HL and higher health care costs and utilization (Berkman et al., 2011). In this case, controlling for comorbidities could have led to an underestimation.

Third, even if our study population was representative for patients with diabetes type 2 in Switzerland, participants and non-participants were significantly different with regard to age, gender, chosen insurance plan, total costs, outpatient costs and number of physician visits. Therefore, the findings of our study cannot be considered to be truly

representative of patients with diabetes type 2 in Switzerland. Furthermore, due to the low number of participants from the French and Italian speaking regions of Switzerland, our results reflect mostly the situation in the German-speaking region of Switzerland. Therefore, our findings cannot be applied to the two smaller language regions with the same reliability as to the German-speaking region. However, our study suggests that even in a country with compulsory health insurance coverage and a renowned healthcare system, HL influences the use of the healthcare system and the healthcare costs. Finally, the observational design doesn't allow to define if any association found was causal.

Besides the limitations of this study, several questions remain unanswered. We used the understanding of written information as a proxy for low functional HL. But the concept of HL contains far more than reading and numeracy skills (Abel, Sommerhalder & Bruhin, 2011; Health Care Communication Laboratory, 2005). Further studies are needed to better understand the broader concept of HL and to improve HL measurements. As this is the first study conducted in Europe to evaluate the relationship between functional HL and healthcare costs and utilization, more studies are needed to investigate the impact of low HL on an individual and societal level.

## Chapter 5

### **Low Health Literacy Associated with higher Medication Costs in Patients with Type 2 Diabetes Mellitus** *Evidence from matched survey and health insurance data*

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*Abstract*

Studies have shown that people with lower levels of health literacy create higher emergency, inpatient and total healthcare costs, yet little is known about how health literacy may affect medication costs.

This cross-sectional study aims at investigating the relationship between health literacy and three years of medication costs (2009-2011) in a sample of patients with type 2 diabetes.

391 patients from the German-speaking part of Switzerland who were insured with the same health insurer were interviewed.

Health literacy was measured by a validated screening question and interview records were subsequently matched with data on medication costs.

A bootstrap regression analysis was applied to investigate the relationship between health literacy and medication costs.

In 2010 and 2011 lower levels of health literacy were significantly associated with higher medication costs ( $p < .05$ ).

The results suggest that diabetic patients with lower health literacy will create higher medication costs.

Besides being sensitive towards patients' health literacy levels, healthcare providers may have to take into account its potential impact on patients' medication regimen, misuse and healthcare costs.

*Keywords*

Health literacy; Medication costs; Healthcare costs; Diabetes; Health insurance data

## 5.1 Introduction

In times of rising healthcare costs, policy makers should be especially interested in understanding the mechanisms underlying the inefficient usage of healthcare services. Health literacy as an underlying variable may play an important role in identifying the causes of using healthcare services inefficiently.

Studies have shown that limited health literacy, which is often defined as the inadequate capacity to read and understand, as well as access “*basic health information and services needed to make appropriate health decisions*” (Nielsen-Bohlman, Panzer, & Kindig, 2004; Selden, Zorn, Ratzan & Parker, 2000), is associated with negative health outcomes. In chronically ill patients for example limited health literacy has been linked to less disease knowledge (Gazmararian, Williams & Peel, 2003; Sayah, Majumdar, Williams, Robertson & Johnson, 2013) and less effective self-care behavior (Mancuso & Rincon, 2006; Osborn et al., 2011; Williams, Baker, Honig & Lee, 1998), which in turn may affect healthcare costs.

Indeed research shows that limited health literacy is associated with increased costs (Franzen, Mantwill, Rapold, & Schulz, 2014; Hardie, Kyanko, Busch, LoSass & Levin, 2011; Howard, Gazmararian & Parker, 2005; Weiss & Palmer, 2004). This suggests that people suffering from lower health literacy have more difficulties in navigating through the healthcare system. They are thus prone to using an inefficient mix of services and in consequence might be more likely to develop more severe diseases that need additional medical attention (Howard et al., 2005).

In that respect medication usage and adherence play an important role. Especially for people suffering from chronic conditions such as diabetes, effective treatment will depend on the accurate intake of prescribed medications, which in turn will influence long-term health outcomes. Possible non-adherence or misuse due to problems of understanding medical information will possibly cause long-term complications and necessitate more usage of healthcare services, creating a revolving-door effect that may increase costs on the healthcare system. It is estimated that diabetes and its long-term complications cause 2.2% of the Swiss total healthcare costs (Schmitt-Koopmann, Schwenkglenks, Spinass & Szucs, 2004).

In addition, adequate health literacy levels are crucial for diabetic patients as they have to be able to follow strict medication and dietary plans and to control their blood sugar levels on a regular basis (Williams, Baker, Parker & Nurss, 1998; Schillinger et al., 2002).

### **5.1.1 Health literacy and medication costs**

So far little is known about the relationship between health literacy and medication costs. Most studies in the field have focused on medication adherence and have provided mixed results (Ostini & Kairuz, 2014). Studies showed that patients with lower levels of health literacy have less understanding of their medication regimen (Marvanova et al., 2011; Persell, Osborn, Richard, Skripkauskas & Wolf, 2007), were less likely to follow-up their medication regimen (Gazmararian et al., 2006; Kalichman, Ramachandran & Catz, 1999; Kalichman et al., 2008; Lindquist et al., 2012) and to adhere to their medication irrespective of the medication management strategy they were using (Kripalani, Gatti & Jacobson, 2010). However, other studies did not find any significant relationship between health literacy and medication adherence (Murphy et al., 2010; Paasche-Orlow et al., 2006), and caregivers of children with lower levels of health literacy were more likely to adhere to prescribed medication regimens (Hironaka, Paasche-Orlow, Young, Bauchner & Geltman, 2009).

Research specifically investigating the relationship between health literacy and medication adherence in diabetic patients also provided mixed results so far. Two studies found significant associations between health literacy and diabetes medication adherence (Osborn et al., 2011) and antidepressant medication (Bauer et al., 2013), whereas another study did not find any relationship (Bains & Egede, 2011).

Few studies have included costs when looking at health literacy and medication usage. One study included more general costs for pharmacy usage when exploring the relationship of health literacy and medical costs among Medicare managed care enrollees. It was found that people with marginal and inadequate health literacy were significantly less likely to use pharmacy services but differences in medication spending were not significant (Howard et al., 2005). Similar results have been found by Hardie

and colleagues (Hardie et al., 2011) who did not find a significant association between health literacy and pharmacy spending.

Yet some researchers have investigated the relationship between health literacy and other healthcare costs (Franzen et al., 2014; Hardie et al., 2011; Howard et al., 2005; Weiss et al., 2004). In the United States (US) it was found that lower levels of health literacy were associated with higher emergency room costs (Howard et al., 2005), higher inpatient costs (Hardie et al., 2011) and higher total healthcare costs (Weiss et al., 2004). On the other hand a study from Switzerland found that health literacy was not associated with inpatient costs but that lower levels of health literacy were associated with higher total and higher outpatient costs (Franzen et al., 2014).

Most studies looking at the relationship of health literacy and costs so far have been conducted in the US with samples that often consisted of participants who were enrolled in Medicare or other health plans with relatively complex drug plans (Piette, Wagner, Potter & Schillinger, 2004). This suggests that people who were not covered by health insurance or any other health plans were excluded from these studies. Yet evidence shows that those who are not insured are more likely to be of lower socioeconomic status (Becker & Newsom, 2003; Franks, Clancy & Gold, 1993) and to have lower health literacy (Howard, Sentell & Gazmararian, 2006; Politi et al., 2014; Sentell, 2012; Yin et al., 2009), which might result in worse health outcomes (Ayanian, Weissman, Schneider, Ginsburg & Zaslavsky, 2000).

The United States Census Bureau estimated that in 2012 15.4% of the population (48 mio.) in the US was not covered by any health insurance plan (DeNavas-Walt, Proctor & Smith, 2013). In contrast to the US, mandatory health insurance in Switzerland has been in place for more than 15 years, guaranteeing coverage for most parts of the population with only few exceptions (Federal Authorities of the Swiss Confederation, 2014). Also, even though medical care in Switzerland has to be co-financed by out-of-pocket payments and was found to prevent some people to use healthcare services when they needed them (Guessous, Gaspoz, Theler & Wolff, 2012), a comparative study showed that in contrast to other countries relatively few insured

people in Switzerland do not receive care or are not able to pay medical bills due to financial reasons (Schoen et al., 2010).

Swiss health plans consist of an excess and a deductible. In exchange for higher premiums insured persons can choose to pay lower annual excess; the minimum threshold set by law is 300 Swiss Francs (CHF). Only once the insured person exceeds the threshold the insurers start covering costs. The insurance will cover 90% of the additional costs and 10% will be covered by the insured person for medical services over and above the excess but by law it is limited to CHF 700 per year (Swiss Insurance Association, 2011). Premiums are subsidized for those having lower income (Schoen et al., 2010), which reduces economic barriers to receive appropriate medication in contrast to what has been suggested by studies from the United States (Mojtabai & Olfson, 2003).

### **5.1.2 Objective**

So far most studies that investigated the relationship between health literacy and healthcare costs used cross-sectional designs measuring costs at one point in time, a design that potentially underestimates the effects found. In addition, as previously stated, most studies have been conducted in the US, where obligatory health insurance has come into place only recently. A large part of the population in the US is still uninsured, making it difficult to obtain data on costs from participants who are potentially more likely to be less health literate and to suffer from worse health outcomes. Therefore, the present study aims at investigating the relationship between health literacy and three years of medication costs (2009-2011) in a sample of insured diabetic type 2 patients in Switzerland, where most of the population is covered by obligatory health insurance plans.

## **5.2 Methods**

### **5.2.1 Study design**

This study was part of a larger survey investigating Swiss diabetic patients' self-management behaviours and their relation to medical costs. Data was collected from a sample of insured persons of the basic health insurance plan of the largest health insurer

in Switzerland. In order to be included in the study, participants had to be between 35-70 years old and not live in a long-term care institution. The age limit was chosen since studies have shown that older age is associated with lower levels of health literacy. Furthermore, due to the mode of data collection by telephone, potential hearing impairments or other disabilities might have made it difficult to conduct interviews.

Given that insurance data was not available on whether possible participants actually suffered from diabetes, only people who had been reimbursed for diabetes medication two years prior to the study were included.

The current study focuses on the German-speaking part because data obtained was more comprehensive for this part than for the two other language regions in Switzerland. A weighted randomized sample of 7'550 persons in the German-speaking part of Switzerland was contacted by letter. In order to be enrolled in the study people had to send back a signed consent form indicating whether they suffered from diabetes type 2. Data collection took place in spring/summer 2012. Interviews in German and Swiss-German were conducted via telephone and lasted up to 25 minutes.

The study was approved by the appropriate institutional review board of the Canton of Ticino in Switzerland (Comitato Etico Cantonale, Bellinzona, Switzerland).

### **5.2.2 Measurements**

#### *Functional Health Literacy*

Functional health literacy was measured by one validated screening item. Since measures such as the Short Test of Functional Health Literacy in Adults (S-TOFHLA) (Baker, Williams, Parker, Gazmararian & Nurss, 1999) or the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993) are not suitable for administration on the telephone, an adapted version of the Chew and colleagues` (Chew, Bradley & Boyko, 2004; Chew et al., 2008) screening question for limited health literacy was used: *“How often do you have problems learning about your medical condition because of difficulty understanding written information?”*. The question has shown to highly correlate with the S-TOFHLA and REALM, thus being a reliable indicator of functional health literacy (Chew, Bradley & Boyko, 2004; Chew et al., 2008).

Translation and back-translation and a pre-test revealed that the question had to be further adapted. This was mainly due to the fact that in Switzerland it is less common to hand out written information in hospital settings or in general practitioners' offices. The question had to be slightly rephrased in order to make it more comprehensible to the study population: "*When you get written information on a medical treatment or your medical condition, how often do you have problems understanding what it is telling you?*" (German: "*Wenn Sie schriftliche Informationen über eine medizinische Behandlung oder Erkrankung an der Sie leiden bekommen, wie oft haben Sie dann Schwierigkeiten diese zu verstehen?*") Responses were scored on a 5-point Likert scale ranging from always to never.

#### *Medication Costs*

Medication costs for the years 2009–2011 were retrieved from the insurer's administrative database (including excess and deductible). Swiss health insurances reimburse all medication that was prescribed by a doctor, including over-the-counter drugs, and which are included in the list of reimbursable pharmaceutical specialities or which are on the list of active substances and other ingredients approved by the federal office of public health (Federal Office of Public Health, 2013).

#### *Control Variables*

Analyses were controlled for sex, age, education, duration of diabetes, insulin use and presence of at least one other chronic condition.

### **5.2.3 Data analysis**

Bivariate associations between functional health literacy and medication costs were calculated separately for each year using Spearman's rank correlation coefficient.

Stepwise regression was used to analyze the relationship between functional health literacy and medication costs. In the first step the control variables were entered and in the second step functional health literacy. Three final models were estimated for each of the three years respectively.

Univariate normality was assessed for each continuous variable using skewness and kurtosis indices. Troublesome skewness and kurtosis values were evident for all three years of medication costs. Therefore, a parameter estimation using bootstrapping (2000 replications) was conducted. All confidence intervals and significance tests reported are from the bootstrap analyses.

## **5.3 Results**

### **5.3.1 Characteristics of participants**

Out of the 7'550 contacted persons 1'486 responded. 732 persons declined participation and 300 persons did not fulfill the inclusion criteria. 454 diabetic patients were eligible to participate but 25 later declined participation, 37 were not reachable, and in one case the interviewed person was not the selected person. Interview data was eventually obtained from 391 participants. Participants and non-participants differed significantly in age, gender and choice of insurance plan. Participants were more likely to be older (65 years and above), male and have chosen the general practitioner model. Significant differences were also found for medication costs in 2011.

The average age was 64 years. 67.8% of participants were male and 59.3% indicated to have obtained a high school diploma or an equivalent certificate. Most participants reported to have suffered from diabetes type 2 from 5 to 10 years. 8 persons reported having diabetes for one year or less, but according to the insurance claims data all participants received diabetes medication for at least 2 years prior to the study. 33.5% of the respondents indicated to use insulin to treat their diabetes and 40.9% indicated to suffer from at least one other chronic condition. (Table 13)

8.7% of the participants reported to have often or always problems understanding written information, whereas most of the participants indicated never having any such problems (Table 14). Health literacy was significantly correlated with education and age ( $p < .05$ ).

Variable	Participants	
	n	%
Total	391	100
Sex		
Male	265	67.8
Female	126	32.2
Age (years)	63,8 ± 6.1 (38-70)	
Education		
No degree	1	0.3
Elementary/Secondary School	50	12.8
High School or general equivalent	232	59.3
Graduate degree	98	25.1
Missing	10	2.5
Diabetes Duration		
3 to 6 months	4	1.0
Up to 12 months	4	1.0
Up to 2 years	29	7.4
Up to 5 years	100	25.6
Up to 10 years	135	34.5
Up to 20 years	99	25.3
More than 20 years	19	4.9
Missing	1	.3
Insulin		
Yes	131	33.5
No	260	66.5
Chronic disease		
Yes	160	40.9
No	231	59.1

**Table 13: Characteristics of study population.**

*“When you get written information on a medical treatment or your medical condition, how often do you have problems understanding what it is telling you?”*

	n	%
Always	11	2.8
Often	23	5.9
Sometimes	65	16.6
Occasionally	109	27.9
Never	183	46.8
Total	391	100

**Table 14: Results of health literacy screening question.**

In 2011, participants had, on average, total costs of medication of CHF 2975.69 (SD=3448.97) and in 2010 CHF 2707.54 (SD=3354.75) and in 2009 the average costs were CHF 2448.97 (SD=2428.37) with 26 missing cases (Table 15).

Year	n	min.	max.	Mean	SD
2011	391	51.30	30'949.80	2975.69	3448.97
2010	391	42.35	35'999.30	2707.55	3354.75
2009	365	0	18'343.10	2448.97	2428.37

**Table 15: Medication costs 2011, 2010, 2009 (Costs in CHF)**  
1 CHF ≈ 1.1 US Dollar

### 5.3.2 Multiple regression analysis

Before the regression analysis, the bootstrap correlations between health literacy and medication costs for each year separately were investigated. A significant correlation was only observed for 2010 ( $r=-.111$ ,  $p<.05$  [CI:  $-.215$ -,  $-.005$ ]).

After having controlled for potential confounders, the regression results showed that health literacy was significantly associated with medication costs in 2010 and 2011. Participants with lower health literacy levels tended to have higher medication costs. Even though the explanatory power of the model was only slightly improved by adding health literacy to the model, the only other variable that remained significantly associated with costs was presence of another chronic condition. In 2009 no significant association was found but the trend remained constant.

From the included confounders only insulin use was significantly associated with medication costs over the range of three years and presence of another chronic condition in 2011 and 2009. None of the other potential confounders was significantly related with the outcome variables. (Table 16)

Linking Health Literacy and Health Disparities

Variable	Step 1			Step 2		
	<i>B</i>	<i>SE B</i>	95% CI	<i>B</i>	<i>SE B</i>	95% CI
2011						
Diabetes Duration	59.714	141.408	-238.363 – 333.942	60.012	139.738	-232.053 – 321.987
Insulin Use	2151.363**	439.982	1325.296 – 3045.059	2101.556**	423.933	1288.800 – 2976.191
Chronic Condi.	701.582*	328.117	31.890 – 1365.523	634.139	328.821	-40.772 – 1261.900
Education	-167.705	323.802	-790.973 – 464.912	-46.009	302.504	-608.559 – 563.862
Gender	-34.480	343.904	-669.356 – 666.141	-51.362	339.412	-695.914 – 633.465
Age	-74.379	39.424	-152.138 – -.152	-62.373	36.085	-134.492 – 5.623
Health Literacy				-455.005*	211.809	-898.285 – -58.298
<i>R</i> <sup>2</sup>	.128			.146		
<i>F</i> for change in <i>R</i> <sup>2</sup>	9.094**			7.898**		
2010						
Diabetes Duration	39.254	168.963	-290.818 – 366.878	39.545	166.957	-292.005 – 352.361
Insulin Use	1354.143**	387.437	615.668 – 2108.277	1305.334**	377.438	602.270 – 2056.105
Chronic Condi.	363.027	330.570	-246.821 – 1045.859	296.936	331.934	-327.724 – 951.655
Education	-293.519	250.376	-792.421 – 185.354	-174.262	236.919	-635.634 – 286.857
Gender	136.111	366.414	-563.658 – 854.862	119.568	361.260	-591.226 – 817.804
Age	-89.392	48.599	-188.372 – -5.699	-77.626	45.335	-171.935 – 1.069
Health Literacy				-445.880*	199.820	-859.469 – -65.610
<i>R</i> <sup>2</sup>	.07			.09		
<i>F</i> for change in <i>R</i> <sup>2</sup>	5.187**			7.601**		
2009						
Diabetes Duration	101.575	127.647	-158.566 – 360.421	103.181	126.168	-151.698 – 354.257
Insulin Use	1304.284**	281.505	738.038 – 1847.748	1273.730**	273.594	729.843 – 1796.196
Chronic Condi.	548.602*	250.936	52.988 – 1039.522	498.267*	247.595	16.979 – 993.906
Education	-409.907	209.932	-829.874 – -.142	-341.164	194.227	-731.474 – 39.335
Gender	128.572	261.649	-383.301 – 696.860	109.018	256.289	-388.924 – 657.106
Age	-38.662	31.437	-105.608 – 16.208	-31.039	29.483	-90.366 – 21.091
Health Literacy				-270.532	150.224	-593.367 – 17.718
<i>R</i> <sup>2</sup>	.110			.123		
<i>F</i> for change in <i>R</i> <sup>2</sup>	7.157**			5.203*		

**Table 16: Summary of hierarchical regression analysis functional health literacy and costs.**

\**p* < 0.05; \*\**p* < 0.01; Comparison groups: no insulin use; no other chronic condition; male

## **5.4 Discussion and conclusion**

### **5.4.1 Discussion**

The current study demonstrated that lower levels of health literacy in diabetic patients were significantly associated with higher medication costs over the range of two years. Even though results for 2009 were not significant, the trend remained constant.

Studies in diabetic patients have shown that patients with lower levels of health literacy have more problems to control their blood glucose levels (Schillinger et al., 2002), which will eventually influence overall health status and increase long-term complications with a higher need for medication.

Given the evidence of a possible relationship between medication adherence and health literacy (Gazmararian et al., 2006; Kalichman et al., 1999; Kalichman et al., 2008; Lindquist et al., 2012), an additional explanation could be that medication costs will increase due to a revolving-door effect following possible non-adherence and unnecessary, potentially preventable, refills. In addition, medication misuse following the non-understanding of drug labels and dosage information might influence long-term health outcomes that will eventually increase medication costs.

Our results are strengthened by the fact that in contrast to the US, where mandatory health insurance was only introduced recently, in Switzerland this obligation has been in place for over 15 years now (Federal Authorities of the Swiss Confederation, 2014). Coverage in Switzerland is rather comprehensive, for those not having the means to afford medical care the possibility to receive subsidies. This suggests that for this study possible non-refills due to economic reasons or missing coverage can be to a large part excluded. However, this may also reduce barriers to ask for unnecessary refills since costs will be reimbursed.

Patients with lower levels of health literacy tend to have less understanding of their condition, therefore they may be more likely to encounter difficulties in discussing treatment decisions with their doctors (Schillinger et al., 2004; Williams et al., 2002). This will eventually lead to situations in which the patient will neglect to discuss, with the doctor, a prior medication regimen or potential misuse leading to increased drug prescriptions. Additional feelings of uncertainty and difficulties in managing a chronic

disease may add to patients` demand for more services, leading to higher costs including medication costs.

Our findings concur with results found by another study conducted in Switzerland, which found that especially people in the German-speaking part of Switzerland have a rather high level of functional health literacy, which is in line with the comparable high educational level in the country (Connor, Mantwill, & Schulz, 2013). Still, our results point towards the fact that also in countries where the educational level is rather high, reading and understanding abilities in the medical encounter may have an influence on health outcomes. Even though Swiss inhabitants are obliged to be insured and subsidies are available for those who do not have the financial means, research needs to look into how health literacy may influence people`s understanding of their health insurance. Given the complexity of the Swiss health insurance system, people may not be aware of their coverage or understand the mechanisms that would allow them to receive financial support. An increased awareness of the services among persons with low levels of health literacy might increase healthcare costs in the short run but might pay off in the long run as they improve their management skills and thus avoid costs created by lack of knowledge, lack of understanding and poor decision-making.

We further believe that similar underlying patterns are also likely to be found in other European countries, where obligatory health insurance has been in place for a sufficient amount of time. However some differences are likely to occur due to different insurance systems, including budget constraints and choice of physicians.

The present study has several limitations. One limitation was that functional health literacy was only measured with one item. Health literacy levels did not vary greatly, suggesting that the chosen item might not have been sufficiently sensitive. Established measures such as the S-TOFHLA or the REALM are more comprehensive measures of functional health literacy but the mode of data collection did not allow for these measures. However, results confirm previous results of a validation study of the S-TOFHLA in the German-speaking part of Switzerland in which 93.6% of participants had adequate health literacy (Connor et al., 2013). Further, given the study design, health

literacy was only measured at one point in time meaning that it was considered to be a static concept. Nevertheless, in the literature health literacy has been widely recognised as being a static concept that only by means of intensive interventions can be improved (Berkman, Davis & McCormack, 2010).

A second limitation arises with the possible underestimation of comorbidities and its effect on medication costs. People with lower levels of health literacy might be more likely to underreport other comorbidities. Even though participants were asked to report on any other chronic condition, no medical data was available to confirm those.

An additional limitation of the study was that even though telephone follow-ups were conducted to increase response rate, the overall response rate was rather low. The data showed that participants differed significantly from non-participants. Besides age, gender and chosen insurance plan, differences in medication costs were found for the year 2011. Further, data has been analysed for the German-speaking part of Switzerland only, not taking the two smaller language regions into account. The results of this study therefore have to be interpreted carefully as they may not be truly representative of the diabetes type 2 population in Switzerland.

Further, given that possible participants were contacted by an invitation letter and were asked to send back a signed consent form, we cannot dismiss the possibility that people who are in general low literate did not attempt to participate in this study.

#### **5.4.2 Conclusion**

Previous studies in the US have found that health literacy and healthcare costs are associated with each other. The current study substantiated these findings by identifying a significant relationship between health literacy and medication costs, also after adjusting for commonly reported covariates. The only relationship that remained significant was presence of another chronic condition. Even though health literacy increased the explanatory power of the model only slightly, the study was able to track the significant relationship between health literacy and medication costs over the range of two years.

Further in-depth research is needed to examine the relationship between health literacy, medication costs and its underlying mechanisms, possibly controlling for more diabetes-specific health literacy and adherence behavior in general.

### **5.4.3 Practice implications**

Results from the current study have implications for practitioners and current diabetes education practice. Doctors and educators might not always be aware of a patient's health literacy level and even less of its impact on healthcare costs and usage. Doctors have to become more sensitive not only towards patients' health literacy levels but also patients' medication regimen and potential misuse. They have to carefully evaluate any other prior medication usage or any other doctor's prescriptions. The study also suggests that in order to provide adequate care for people with diabetes, information provision alone might not be sufficient. In the case of this study, participants have, as part of their insurance, access to several forms of diabetes education, including telephone and private counseling. Still, people with lower levels of health literacy had higher medication costs, suggesting that diabetes education was less successful for them than for their counterparts with higher levels.

**Part III**

Health Literacy and Health Disparities

## Chapter 6

# Exploring the Role of Health Literacy in Creating Health Disparities *A Conceptual Discussion*

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*Abstract*

It has been largely agreed upon that health literacy is an underlying mechanism leading to health disparities. However, still relatively little is known about the precise nature of this mechanism and how health literacy, as a potential intervenable variable, might reduce disparities, as intervention research has not demonstrated this to date.

This paper describes conceptual and measurement issues that might have prevented more systematic research on the relationship between health literacy and disparities. Implications for interventions are also presented.

We discuss conceptual pathways on how to theorize the relationship and provide recommendations on how to integrate research on health literacy more systematically into research on health disparities and vice versa.

*Keywords*

Health Literacy; Health Disparities; Race/Ethnicity

## 6.1 Introduction

The term health disparities was coined around 1990 and mainly refers to worse health among socially and/or economically disadvantaged people within any society or collective relative to their counterparts (Braveman, 2014). Healthy People 2020 (U.S. Department of Health and Human Services (HHS), 2010) defined economic, social and environmental disadvantages as potential drivers of health disparities.

Social disadvantages, which in general refer to an overall unfavorable position within a social hierarchy (Braveman, Egerter, & Williams, 2011; Braveman, 2014), are often a byproduct of low socioeconomic status (SES). Low SES is mostly operationalized as having lower income and less education, but also includes being unemployed or not being covered by health insurance (Adler & Newman, 2002).

In the US, racial and ethnic minorities have been disproportionately burdened with illness relative to Whites. Minorities also have lower SES, which has been found to be a driver of disparities in the performance of health behaviors, the diagnosis of disease, its prevalence, progression and mortality (Adler & Newman, 2002).

Studies in diabetes patients for example have shown that non-Whites are more likely than Whites to underuse medications for cost-related reasons (Ngo-Metzger, Sorkin, Billimek, Greenfield, & Kaplan, 2012; Piette, Heisler, Harand, & Juip, 2010; Tseng et al., 2008). Still, there is conflicting evidence about whether this is actually due to differences in SES. Whereas one study reports that differences in SES drive this relationship (Tseng et al., 2008), two others report that the relationship persists regardless of SES differences (Ngo-Metzger et al., 2012; Piette et al., 2010). Even if differences in SES drive disparities in cost-related non-adherence, it is difficult to intervene upon someone's income, education, employment status, and in some instances, insurance status. In addition, there is evidence suggesting that changing one's SES might not improve health behaviors (Ngo-Metzger et al., 2012; Piette et al., 2010). Given the complexity of potential producers of health disparities, we need to identify intervenable factors - that is factors other than SES - that contribute to disparities in health (Paasche-Orlow & Wolf, 2010).

An intervenable factor linking for example racial status to health outcomes is patients' health literacy skills or their ability "*to obtain, process and understand basic health information and services needed to make appropriate health decisions*" (Nielsen-Bohlman, Panzer, & Kindig, 2004). Limited health literacy is common (Kutner, Greenburg, Jin, & Paulsen, 2006; Rudd, 2007), and has been, amongst others, associated with lack of adherence to recommended self-care activities (Federman et al., 2014; van der Heide et al., 2014; White, Chen, & Atchison, 2008), worse general health (Wolf, Gazmararian, & Baker, 2005; van der Heide et al., 2013), and pre-mature mortality (Baker et al., 2007). Racial/ethnic minorities in the US are disproportionately affected by low health literacy, with an estimated 41% of Hispanic Americans and 24% of African Americans as, compared to 9% of Non-Hispanic Whites, having below basic health literacy skills (Kutner et al., 2006).

Programs have been developed and implemented to improve patients' health literacy skills and provide relevant information in order to reduce disparities (CDC, 2015). However, there is little knowledge on how health literacy actually contributes to health disparities, and only a few studies have explored this issue so far (Bennett, Chen, Soroui, & White 2009; Osborn, Paasche-Orlow, Davis, & Wolf, 2007; Osborn et al., 2011; Sudore et al., 2006).

This paper aims at discussing the persistent lack of more comprehensive research by identifying conceptual and related measurement issues that prevent health literacy to be integrated more systematically into research on health disparities. In addition, the present work attempts to describe how these issues have so far prevented the systematic integration of the concept of health literacy into interventions that aim at reducing health disparities.

## **6.2 Health literacy and health disparities**

Even though it is assumed that "*limited health literacy follows a social gradient that can reinforce existing inequalities*" (Kickbusch, Pelikan, Apfel, & Agis, 2013), few studies have examined whether health literacy might contribute to health disparities.

Health disparities are often conceptualized as an outcome of a number of mediating mechanisms. In particular, mechanisms that include behavioral factors affected by resources, culture or the environment have received increased attention in health disparities research (Roux, 2012). In this regard, health literacy is often hypothesized as being a mediating factor between SES and health behaviors or access to healthcare (Manganello, 2008; Paasche-Orlow & Wolf, 2007, von Wagner, Steptoe, Wolf, & Wardle, 2009). Some studies have tested these pathways looking at racial disparities, and found that health literacy mediates the relationship between race and self-rated health status (Bennett, 2009), quality of life (Curtis, Wolf, Weiss, & Grammer, 2012), and medication adherence (Osborn et al., 2007; Osborn et al., 2011). Health literacy has also been found to mediate the relationship between education and a number of clinical outcomes, such as glycemic control in diabetes patients (Schillinger, Barton, Karter, Wang, & Adler, 2006), self-rated health (Bennett et al., 2009; van der Heide, 2013), and health-related knowledge (Lindau et al., 2002). However, other studies investigating these potential path models found other variables, such as knowledge or self-efficacy, to be more important predictors (Osborn, Cavanaugh, Wallston, & Rothman., 2010; Osborn, Paasche-Orlow, Bailey, & Wolf, 2011; Mancuso & Rincon, 2006).

There is still a substantial need for more empirical research in order to understand the nature of health literacy as a contributing factor to health disparities and to potentially disentangle it from other adjacent constructs, such as education or age for example, two variables that are often strongly associated with health literacy skills.

The current lack of a more comprehensive integration of health literacy into research on health disparities might be due to three reasons, which will be presented and discussed in the following order:

- (i.) the general lack of definitional and conceptual clarity of the term health literacy, leading to
- (ii.) difficulties in operationalizing health literacy for research purposes and to develop appropriate measures, creating

- (iii.) a lack of cohesive evidence on how to systematically integrate the concept of health literacy into research and interventions on health disparities.

### **6.2.1 Conceptual clarity**

Even though it is generally agreed upon that health literacy is a multidimensional concept, there is still no commonly accepted agreement on what health literacy entails (Baker, 2006; Berkman, Davis, & McCormack, 2010; Frisch, Camerini, Diviani, & Schulz 2012).

The term health literacy encompasses different skills relevant to understanding and acting upon information relevant for one's health. Functional health literacy for example refers primarily to reading, writing and numeracy skills in the medical environment. Other dimensions may include communicative health literacy, which refers to more advanced skills that allow the individual to extract and derive meaning from information and different sources and to act upon it, and critical literacy, which includes cognitive and social skills to be used to critically assess information and use it accordingly (Nutbeam, 2000).

The broadness of the concept and its different dimensions pose equal challenges for researchers to appropriately include it into their research (Baker, 2006). The World Health Organization (WHO) for example uses a rather broad definition of health literacy that not only includes concepts of access, understanding, and use of information, but also highlights the importance of the contexts within which individuals engage with information. This definition also links health literacy to broader concepts of health, including being empowered to engage with one's health and the determinants of health (Kickbusch & Nutbeam, 1998). The study of health disparities increasingly relies on this ecological perspective. Multi-level factors drive disparities (e.g. individual work setting or the political setting in general) and, accordingly, solutions are expected to require multi-level action. Following Bronfenbrenner's description of ecological forces (2005), we are prompted to place the individual with limited health literacy at the center of the discussion and then assess the family, network, community, institutional, political, and

cultural influences on health behaviors and outcomes. In this way, we can identify: 1) diverse impacts of limited health literacy and 2) opportunities to intervene.

This perspective might be accommodated by two conceptual approaches to health literacy that have been brought forward by Nutbeam (2008). From a medical care perspective, health literacy has been mainly conceptualized as a “clinical risk”, whereas the public health perspective defines health literacy as a “personal asset” (Nutbeam, 2008; Sørensen et al., 2012). The idea of “clinical risk” in the context of health literacy might refer to a patient’s inability to read important medical information. Research thus far has primarily focused on identifying health literacy as a risk factor, i.e. investigating how health literacy affects health behaviors and outcomes, and, ultimately, appropriate responses to the problem. The conceptualization of health literacy as a “personal asset”, on the other hand, refers to the potential alterability of one’s health literacy levels. In contrast to the conceptualization of health literacy as a “clinical risk,” this conceptualization rather focuses on system level factors that enable patients to use and develop their literacy skills, eventually leading to better health outcomes. This part of the conceptualization has received less attention (Nutbeam, 2008), and further research on health literacy in the context of health disparities may indeed help to address this gap.

One of the main questions that health disparities research wants to answer is how and why certain groups are more vulnerable than others to certain health outcomes. There seems to be the general agreement that health disparities can only be measured with regard to a reference point (Braveman, 2006). These comparisons can be conducted, for instance, between the group one is interested in and the general population, or between the most advantaged group of a society and any other group (Keppel et al., 2005). It is not necessarily a comparison between those that have better and worse health, but between those who are likely to be socially better off and those who are not (Braveman, 2006). Still, most of the research on health literacy has mainly focused on identifying differences *within* populations and has not systematically investigated how health literacy may be distributed *between* populations that can be compared to each other, and how this is related to specific health outcomes. For example, Non-White race might be more strongly associated with worse health outcomes

when health literacy is low and vice versa, suggesting a moderator effect. Other results might be found for educational disparities, in which health literacy might not be a moderator but instead becomes a mediator in this relationship (Figure 2). More research is needed to take these possible pathways into account. Further, only systematic comparisons between groups will allow to understand in how far health literacy accounts for the health disparities observed.

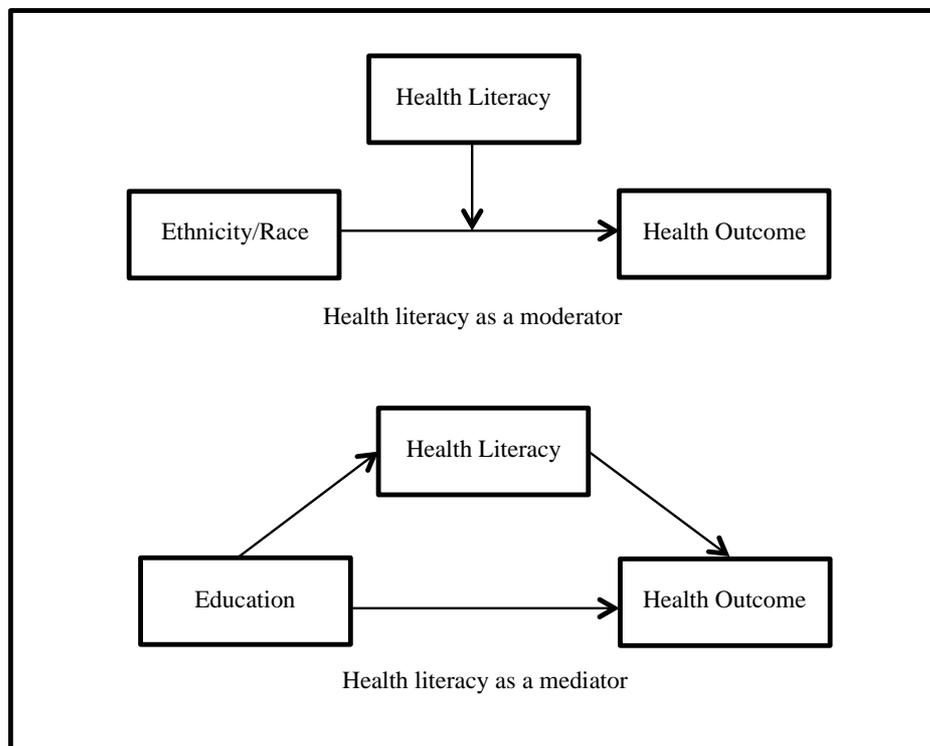


Figure 2: Potential role of health literacy in creating disparities.

### 6.2.3 Measurement

The lack of conceptual clarity of health literacy might have led to the fact that most empirical work has focused on its functional component. Several measures assess functional health literacy, including the Short Test of Functional Health Literacy in Adults (S-TOFHLA) (Baker, Williams, Parker, Gazmararian, & Nurss, 1999) or the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993), both aimed at capturing reading skills in the healthcare setting. Other measures such as the

Newest Vital Sign (NVS) (Weiss et al., 2005) or the General Health Numeracy Test (GHNT) (Osborn et al., 2013) were specifically developed in order to test for health numeracy skills. Even though these measures are often decontextualized from any specific disease or health outcome, they have not been systematically integrated into research on health disparities. Some of the explanation may lay in the fact that those measures mostly focus on clinical contexts, testing for words and numeracy issues relevant to the medical setting. Also, these tests do not provide any indication on leverage points, such on how to improve and influence the measured skills. Moreover, studies have shown that measures of functional health literacy may not be equally reliable in different populations, pointing towards a lack of generalizability of these measures (Fransen, Van Schaik, Twickler, & Essink-Bot, 2011; Jordan, Osborne, & Buchbinder, 2011).

Other health literacy measures still largely vary in conceptualization and operationalization of health literacy, as well as in their administration styles, whether it is self-reported or performance-based (Haun, Valerio, McCormack, Sørensen, & Paasche-Orlow, 2014). Some attempts have been made to develop more specific measures that evaluate disease-specific literacy, such as cancer (Diviani & Schulz, 2012; Williams, Mullan, & Fletcher, 2007) or asthma literacy (Londoño, & Schulz, 2014). Still, these measures primarily assess health knowledge. Even though the literature has recognized its value in understanding health literacy (Frisch et al., 2011) and its relationship with functional health literacy (Gazmararian, Williams, Peel, & Baker, 2003; Williams, Baker, Parker, & Nurss, 1998), they may pose a conceptual difficulty for health disparities researchers. Definitional boundaries start to blur and adjacent concepts may be less clearly distinct. This will eventually blow up the operationalization of health literacy, which might - in the worst case - lead to a kitchen-sink approach of measuring all relevant concepts possible. In addition, and similar to the functional literacy measures, the specificity of these knowledge tests focusing on clinical settings may impair their comparability across different contexts (Frisch et al., 2011).

Some health literacy measures have included concepts such as information seeking and processing (Jordan et al., 2013; Sørensen et al., 2013). From a health

disparities perspective these measures might be more meaningful, as they can serve as identifier of where to leverage communication efforts in order to reduce the negative effects of limited health literacy. It has been shown that the same social determinants associated with health disparities, respectively health literacy, such as race, ethnicity, class, and geography, are also strongly associated with communication inequalities (Blake, Flynt-Wallington, & Viswanath, 2011; Viswanath, 2006; Viswanath & Ackerson, 2011). Communication inequalities have been documented along 5 broad dimensions: (i) access to and use of communication technologies and media, (ii) attention to health information, (iii) active seeking of information, (iv) information processing, and (v) communication effects on health outcomes. It has been proposed that communication inequalities mediate the relationship between social determinants and outcomes along the cancer continuum for example, and thus serve as one explanation for health disparities (Viswanath, Ramanadhan, & Kontos, 2007). These dimensions are well in line with the possible moderator or mediator role that health literacy might play in the relationship between social determinants and health disparities (Hovick, Liang, & Kahlor, 2014).

#### **6.2.4 Interventions**

Given the largely assumed role of health literacy as a potential underlying factor for socioeconomic differences in health, it has become particularly attractive to think of it as an intervenable variable in reducing health disparities (Parker, Ratzan, & Lurie, 2003). Besides healthcare practitioners and researchers, also policy makers have recognized the need to focus on health literacy in order to reduce disparities and to push efforts forward to integrate it more systematically into the healthcare agenda (HHS, 2010b). Likewise, recent work by the WHO highlights the potential for health literacy to serve as a community asset and an important source of social capital (Kickbusch et al., 2013).

In the clinical setting, the problem of limited health literacy has been addressed through a number of recommendations (DeWalt et al., 2010; Joint Commission, 2007; National Institutes of Health, 2015). These recommendations focus on accommodating patients with limited health literacy by using such things as plain language or the teach-

back method in order to test and clarify misunderstandings between patients and healthcare providers (Osborn et al., 2010). However, health literacy skills as a potential intervenable variable cannot be improved per se. Therefore, it is recommended to assume that in general anyone may have difficulties in understanding information relevant to her/his health (DeWalt et al., 2010). However, most interventions in the field of health disparities seem to assume a rather high level of health literacy, excluding those groups that are likely to be afflicted by limited health literacy (El-Khorazaty, 2007; Gauthier, & Clarke, 1999). Recommendations should therefore be equally applied to interventions in the field of health disparities and broadly. There is a need to ensure that all interventions incorporate clear, simple and compelling health communication. This is a strategy that will benefit all audiences, not just those who may have lower levels of functional health literacy. These concepts are essential for providing effective communication and connecting audiences to information and services to improve their health, but are often overlooked or set aside because the cost in time and resources are deemed too great by researchers, practitioners, and funders (Coulter, & Ellins, 2007).

We currently see a sea change in the ability to reach populations who have limited literacy. New technologies allow to provide simple and compelling visuals, to use patient/audience information to tailor messages to the individual and to let users interact with information in a way that suits their own learning style. However, even though promising to overcome barriers related to limited health literacy, relatively little is known yet on how individual health literacy and technology use interact. Some evidence points to the fact that limited health literacy is an additional barrier to accessing and using online information and portals (Chakkalakal, Kripalani, Schlundt, Elasy, & Osborn, 2014; Mayberry, Kripalani, Rothman, & Osborn, 2011; Sarkar et al., 2010.). Thus, it may potentially increase the gap between high and low health literate individuals (Sarkar et al., 2010).

### **6.3 Discussion**

There is a well-established relationship between health literacy and health outcomes. This relationship means that health literacy is very likely to affect opportunities for

health and health outcomes, which, when not equitably addressed, produce health disparities. It is also well established that health literacy correlates with many of the antecedents of health disparities such as race or education. Both reasons suggest that an effort should be made to conceptualize and systematically investigate the relationship between the two concepts.

Conceptual models of health disparities have focused amongst others on genetic or structural factors, as well as the interplay between genetics and environment as contributors to health disparities. Pathway models on the other hand conceptualize health disparities as an outcome of a number of mediating mechanisms. These mechanisms include behavioral factors that are affected by resources, culture or the environment. (Roux, 2012) As a starting point, one may differentiate between three overlapping mechanisms of how health literacy and health disparities may be linked:

- health literacy as a mediator between social inequalities and health disparities,
- health literacy as a moderator of these effects, and
- health literacy as an independent producer of health disparities.

The notion of health literacy as a mediator means that health literacy might be the mechanism by which other antecedents of health disparities exert their influence. A short scoping review revealed that indeed most of the research on health literacy and health disparities seems to investigate health literacy as a potential mediator in this relationship (Bennett et al., 2009; van der Heide et al., 2013; Hovick et al., 2014; Schillinger et al., 2006; Waldrop-Valverde et al., 2010). On the other hand, a couple of other studies have investigated health literacy as a moderator to the disparity-producing capacity of social factors (Bains & Egede, 2011; Langford, Resnicow, Roberts, & Zikmund-Fisher, 2012; Pandit et al., 2009).

In the case of health literacy being a potential independent producer of health disparities (Pandit et al., 2009; Waite et al., 2013), research is not primarily aiming at sorting out which associations between antecedents of health disparities and health outcomes remain, but it rather intends to describe the role of health literacy in creating

health disparities. Whether health literacy plays an independent role in creating health disparities depends on the presence of intrinsic mechanisms that might explain an effect. Such mechanisms can be easily imagined for health literacy, such as e.g. communicative competence. If it matters what your doctor says, then misunderstanding him/her also matters, independent from any existing social inequality.

Besides examining health literacy solely as a factor that might potentially explain and produce health disparities, one must also look at health literacy as a potential leverage factor to reduce disparities. The above-mentioned roles thus suggest different assessments of the possibility to reduce some of the disparities through health literacy interventions. If health literacy is an independent predictor, health disparities created by social inequalities will not be affected by health literacy interventions. On the other hand, if health literacy is found to be a mediator, the potential of health literacy interventions depends on the existence of other mediators or mechanisms, such as motivation or self-efficacy (Paasche-Orlow & Wolf, 2007). The moderator role suggests that potentially part of the health-related effects of social inequality might be assuaged by, for instance, increasing patients' communicative capacities, but that also would depend on the presence of other moderators.

Attention is prompted to address opportunities that may exist for providers, community organizations, institutions (including, but not limited to, healthcare facilities), governments, and organizations using for example mass media to account for health literacy as part of their efforts to improve health, broadly, and address health disparities, specifically. An ecological, systems-focused perspective allows to assess the individual engaging with information and the systems within which that information is encountered, greatly broadening the potential intervention strategies (Koh et al., 2012).

## **6.4 Conclusion**

Health literacy and health disparities are both analytically not very sharp terms. Health disparities, for instance, can be understood as the variance that occurs between groups of human beings with regard to their health status, risk of morbidity, chances for successful treatment, or mortality. Health disparities are understood as being caused and aggravated

by social inequalities. The usual commitment of health-related research to improve health is amplified in this tradition by a commitment to social justice, which easily turns into advocacy of social reform aiming not only at eliminating health disparities but also going to the root of the matter and remove the inequalities that caused them. This focus may have contributed to the fact that health disparities research has often overlooked health literacy, which is a concept rooted much more in psychology and sociology. Vice versa, the reformist stance of health disparities research may have alienated many scholars active in health literacy with its focus on small-scale concrete improvements such as increasing the readability of patient information material or testing interventions aimed at better patient-doctor communication.

We make three propositions that should serve as pointers for those working in the field of health literacy and disparities. These recommendations are by any means not exhaustive but should provide preliminary guidance on how to plan and layout research on health literacy and disparities.

**1. Conceptualizing Health Literacy** – Health literacy should be conceptualized according to the health disparity under investigation and its potential role in the relationship. Reference groups (e.g. race, income, etc.) should be carefully evaluated against each other to explore the role of health literacy in the relationship. Whether defined as a mediator, moderator or independent predictor, each possible pathway should be taken into consideration and carefully evaluated in order to understand its potential explanatory power.

**2. Measuring Health Literacy** – In order to measure the potential influence of health literacy on health disparities and to choose appropriate measurements, one should clearly identify the health disparity under investigation beforehand. Individual and social environmental factors that influence individual health and drive the health disparity under scrutiny should be investigated and be reflected in the choice of health literacy measures. Reference groups should be held constant and carefully evaluated against each other.

**3. Designing and Implementing Interventions** – Recommendations to accommodate for limited health literacy in the clinical settings should be also given appropriate consideration when designing interventions aiming at reducing disparities in health. Strategies, such as using plain language for example, are essential in reaching those populations that might otherwise fall off the radar. New technologies to reach these populations are indeed promising but need to be carefully examined to understand if they provide the expected effects. Especially in populations which show limited health literacy or are particularly afflicted by health disparities, interventions that use technologies need to be developed in accordance with the populations' needs and abilities.

One of the interesting challenges in identifying and operationalizing the role of health literacy in creating disparities and intervening on them, may be that taking a life course perspective is vital for the study of health disparities (Braveman, 2014). We may need to shift our thinking about health literacy in the same way and think of it as a life-long capacity-building process. This not only allows for changing the social contexts individuals face over the lifespan, but it also allows for the rapidly changing information and communication environments, which increasingly place pressure on individuals to actively find and consume health information. This can in turn have important implications for health disparities (Viswanath et al., 2012).

## **Chapter 7**

# **The Role of Health Literacy in Explaining Health Disparities**

*A Systematic Review*

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*Abstract*

Health literacy is commonly associated with many of the antecedents of health disparities. Yet the precise nature of the relationship between health literacy and disparities remains unclear.

A systematic review was conducted with the aim to contribute to a better theoretical understanding on how health literacy contributes to health disparities.

Five databases were searched for peer-reviewed studies. Publications were included in the review when they (1) included a valid measure of health literacy, (2) explicitly conceived a health disparity as related to a social disparity, such as race, ethnicity, culture or gender and (3) when results were presented by comparing two or more groups afflicted by a social disparity investigating the effect of health literacy on health outcomes. Two reviewers evaluated each study for inclusion and abstracted all relevant information.

Thirty-six studies were included in the final synthesis. Some evidence was found on the mediating function of health literacy on self-rated health status across racial/ethnic and educational disparities, as well as on the potential effect of health literacy and numeracy on reducing racial/ethnic disparities in medication adherence and understanding of medication intake. However, studies largely varied with regard to the health outcome under investigation and the health literacy assessments used. Further, many studies lacked a specific description of the nature of the disparity that was explored and a clear account of possible pathways tested.

*Keywords*

Health Literacy; Health Disparities; Systematic Review; Social Determinants

## 7.1 Introduction

Health disparities are differences in health that occur due to social, economic or environmental disadvantages. In particular, groups that are more likely to fall victim of discrimination or segregation are also more likely to face increased difficulties in preserving their health (People 2020). In the United States (US), for example, those with lower education, less income and individuals from ethnic/racial minorities are more often afflicted by worse health (Braveman, Cubbin, Egerter, Williams, & Pamuk, 2010; Kennedy, Kawachi, Glass, & Prothrow-Stith, 1998). However, not all differences in health also correspond to health disparities. Certain differences are natural and are likely to occur for other reasons than being socially, economically, or environmentally disadvantaged (Braveman, 2006; 2014). Examples are differences between younger and older populations, or being in a work position that is more prone to accidents than others (Braveman, 2014). Health equity, on the other hand, refers to the potential of reducing barriers to access to healthcare by, for instance, creating fair opportunities, and ensuring that distribution is not influenced by social standing (Braveman, 2006; Whitehead, 1991). Disparities in health are mostly measured by comparing two or more groups to each other or to a reference group in general. Likely one or more disadvantaged groups are compared to a more advantaged group, using an indicator of health or health-related outcome (Braveman, 2006; Keppel et al., 2005).

Scholars in the field of health literacy, defined as the *“degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions”* (Nielsen-Bohlman, Panzer, & Kindig, 2004), have largely agreed that disparities in health are often linked to health literacy. It has been shown to be related to many of the drivers of health disparities. Individuals likely to fall victim to social disparities, which in turn lead to worse health outcomes, are also more likely to have lower levels of health literacy. Studies have shown for example that non-Whites have more often limited health literacy than Whites (Berkman et al., 2011; Kutner, Greenburg, Jin, & Paulsen, 2006; Wolf, Gazmararian, & Baker, 2005). Also, factors such as lower income or education have been found to be related to lower levels of health literacy (Baker et al., 2002; von Wagner, Knight,

Step toe, & Wardle, 2007), which has led to the assumption that health literacy and disparities are connected with each other.

Healthcare practitioners and researchers, as well as policy makers, have recognized the need to focus on health literacy, as a potential intervenable factor by which health disparities can be reduced (Koh et al., 2012; National Institutes of Health, n.d.). Still, the precise nature of their relationship is not clear. Until today, most of the evidence available on their relationship seems to be relatively arbitrary. Consequently, also potential explanatory pathways and conceptualizations on how health literacy contributes to disparities remain rather vague.

Adding to Berkman and colleagues' work (2011), a systematic review was conducted to understand in how far the relationship between health literacy and health disparities has been systematically investigated and which potential relationships and pathways have been identified. In doing so, the review seeks to contribute to a better theoretical understanding on how health literacy contributes to disparities, to identify gaps and missing links that might warrant further investigation, and to better understand potential leverage points for research, as well as for interventions that aim at reducing disparities.

## **7.2 Methods**

### **7.2.1 Search strategy and inclusion criteria**

A review protocol was developed and reviewed by two experts in the field of health literacy and health disparities. To identify relevant published articles the following databases were systematically searched: Cochrane Library, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Educational Resources Information Center (ERIC), PsycInfo and PubMed/Medline. Searches were not limited to any specific time frame or specific language.

The search terms for “health disparities” included related concepts such as “inequality”, “race”, “minority” or “gender” that had been identified previously using a scoping search. For “health literacy” other terms such as “reading”, “writing” and “numeracy” in combination with “health” were included. Truncations (wildcard searches)

(\*), hyphens and other relevant Boolean operators were used to make the search as sensitive as possible (Figure 3). Appropriate MeSH terms were used for searches in PubMed. Electronic searches were supplemented by hand searches, and search alerts were set until February 2015. Reference lists of the included articles were further reviewed to identify remaining studies.

<b>Concept 1</b>		<b>Concept 2</b>	
<b>Health Literacy</b>		<b>Health Disparities</b>	
Health Literacy		Health Disparities	
OR		OR	(disparit*) OR
Literacy		OR	(inequality*) OR
OR		Health Care Disparities	(minority) OR (raci*)
Reading		OR	OR (race) OR
OR	<u>AND</u>	OR	(discrim*) OR (gender)
OR		Health Status Disparities	OR (sex) OR (disab*)
Writing		OR	OR (wom*) OR
Or		OR	(child*) OR (ethn*)
Numeracy		Health Inequalities	OR (immigr*) OR
AND		OR	(migr*) OR (income)
Health		Minority Health	OR (poverty) OR
			(SES) OR
			(socioeconomic)
			OR (religi*) <sup>1</sup>

**Figure 3: Overview of search strategy**  
<sup>1</sup>for demonstration puposes only the last search terms include Boolean operators

Articles were included when they (1) were peer-reviewed (dissertations excluded), (2) included a valid measure of health literacy (direct or indirect), (3) explicitly conceived health disparities as related to a social disparity, such as race, ethnicity, culture or gender and (4) when results were presented by comparing two or more groups afflicted by a social disparity investigating the effect of health literacy on health outcomes. It was *not* sufficient if, for instance, a difference in health literacy

levels between two racial groups was reported as a secondary outcome. Further, age was not considered a predictor of health disparities, for the reasons described above (Braveman, 2014).

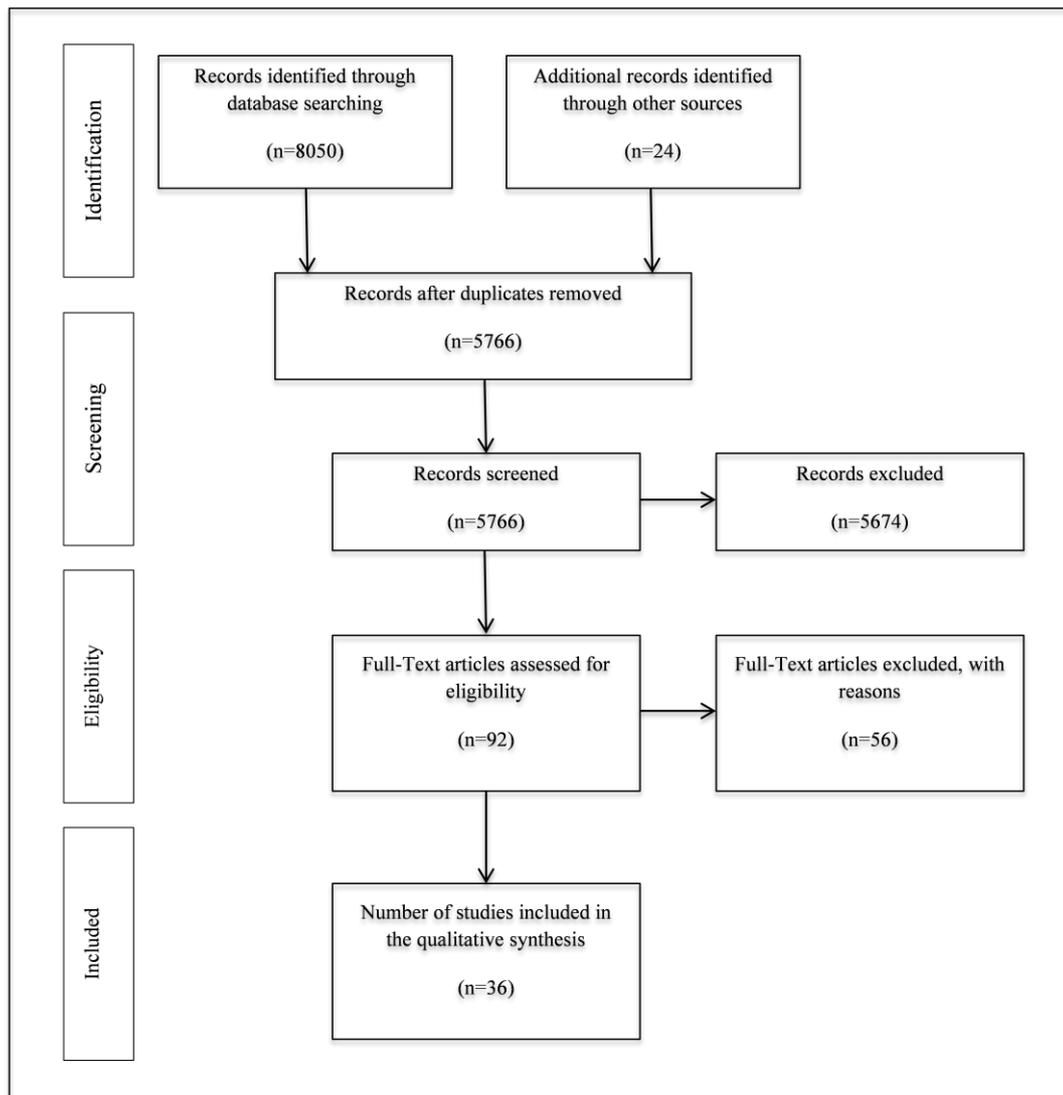
Any observational study, including cross-sectional, cohort and case-control, examining the relationship between health literacy and health disparities was considered, as well as any experimental study testing for disparities with regard to health literacy. Studies had to report on the association between the disparity under investigation and health literacy. Studies that measured solely disease knowledge were excluded.

### **7.2.2 Screening process**

After having extracted relevant abstracts from the databases, one reviewer screened all abstracts and titles for duplicates. In a second step two reviewers screened the abstracts for relevance to be included in the review. Discrepant assessments were resolved by discussion. Full manuscripts were retrieved for those abstracts that were identified to be relevant. Two reviewers independently extracted data from the selected studies, using a pre-designed data extraction form, which had been piloted before. Data were synthesized for final analysis and systematically screened by the two reviewers to ensure the correctness of the information.

Based on criteria defined by Berkman and colleagues (2011), the same reviewers independently rated the quality of articles. Studies were evaluated either as good, fair or poor. The quality assessment tool took such things as selection bias, measurement bias and confounding variables into consideration. Also here disagreement was resolved by consensus finding.

Given that study characteristics varied with regard to health literacy measures, health outcomes, sample sizes and characteristics, it was not deemed feasible to carry out a meta-analysis. Therefore a narrative analysis was conducted. Findings were ordered according to health outcomes and the disparities identified and the role of health literacy in explaining the disparity under investigation. Only the association between health literacy and the relevant outcome variables was extracted, even though some of the studies might have reported on additional relationships.



**Figure 4: Flowchart of screening process.**  
 (adapted from: Moher, D., Liberati, A., Tetzlaff, J., & Altman, 2009)

### 7.3 Results

After the removal of duplicates, 5766 abstracts were reviewed and 92 articles were included for full revision. 36 articles were included in the final synthesis<sup>3</sup> (Figure 4).

Most studies had been conducted in the US, except for five studies that had been conducted in Canada, China, the Netherlands and the UK.

Nine studies focused on racial/ethnic and educational differences and investigated disparities in self-reported health. Six studies looked into how health literacy might explain differences with regard to cancer, including disease progression and information seeking. Another six studies investigated the impact of health literacy and numeracy on medication adherence and management with regard to racial/ethnic disparities.<sup>4</sup> Five studies, of which one was an experimental study, scrutinized the explanatory power of health literacy and numeracy on disease control and its potential of reducing effects for race/ethnicity and education.

An additional four studies investigated racial/ethnic and educational disparities with regard to preventive care behavior<sup>5</sup>. Three studies investigated the role of health literacy in explaining racial/ethnic disparities with regard to end of life decisions.

An additional six studies were identified that looked at other various outcomes, such as physiological health or usage of complementary and alternative medicine.

Some of the studies used multiple health literacy measures but the most commonly used measure was the Rapid Estimate of Adult Literacy (-Revised) (REALM-R) (Davis et al., 1993), which was applied in 15 studies. It was followed by the (Short)-Test of Functional Health Literacy (S-TOFHLA) (Baker, Williams, Parker, Gazmararian, & Nurss, 1999), which had been used in 10 studies. Other measures included the Health Activities and Literacy Scale (HALS) (Rudd, 2007) and the health literacy items in the National Assessment of Adult Literacy (NAAL) (Kutner et al., 2006). Only two studies

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<sup>3</sup> The authors are aware that also Bakker, O'Keeffe, Neill, & Campbell, 2011; Chakkalakal, Kripalani, Schlundt, Elasy, & Osborn, 2014; Chaudhry et al., 2011; Kaphingst et al., 2015; Sarkar et al., 2010; Sudore et al., 2006 have looked at similar relationships. However, it was decided to exclude them, as they did not elaborate sufficiently on the relationship or did not explicitly acknowledge the relationship under investigation.

<sup>4</sup> Yin et al. (2009) reported on "Medication Adherence & Management" and "Other Outcomes".

<sup>5</sup> Bennett, Chen, Soroui, & White, S. (2009); Howard, Sentell, & Gazmararian (2006) reported on "Self-reported Health Status" and "Preventive Care".

used the screeners for limited health literacy developed by Chew and colleagues (2008), as well as the Newest Vitale Sign (NVS) (Weiss et al., 2005). Only five studies were identified that tested numeracy skills (Annex).

### **7.3.1 Self-reported health status**

Eight studies investigated in how far health literacy might explain racial disparities in self-reported health status. Two studies found that health literacy mediated or respectively reduced the effect of race/ethnicity and education on self-reported general health (Bennett, Chen, Soroui, & White, 2009), including physical and mental health (Howard, Sentell, & Gazmararian, 2006).

Three studies explored the link by focusing on Asian American groups and found mixed evidence. In one study, health literacy was significantly associated with self-reported health status and depression symptoms in White and Asian immigrants in general. However, when disaggregated in separate groups, health literacy was only significantly associated with self-reported health status in Chinese and Korean participants (Lee, Rhee, Kim, & Ahluwalia, 2015). Similarly another study found that low health literacy was significantly associated with poor health status in Japanese and Filipinos, as well as in White participants (Sentell, Baker, Onaka, & Braun, 2011). On the other hand, another study found that limited English proficiency (LEP) was a more important predictor than health literacy in explaining differences in self-reported health status in Hispanics, Vietnamese, Whites and “other races”. Low health literacy was only significantly related to health status in Whites and “other races” but not in any Asian group. Further, Chinese, Vietnamese, Hispanics and “other races” with low health literacy *and* LEP had the highest odds of poor health status (Sentell & Braun, 2012).

Similar patterns were identified in Canada (Omariba & Ng, 2011). Even though health literacy was significantly associated with good self-rated health, discordance between native language and language of data collection reduced the effect of health literacy to non-significance. Similarly, another study from Canada found that among different generations of immigrants, health literacy was significantly associated with

reported disability but the effect was largely accounted for by differences in education, employment and income (Omariba & Ng, 2014).

In one study from China, which compared two ethnic groups, health literacy was significantly associated with prevalence of pain in a minority group. There was also a significant interaction effect between health literacy and ethnicity on self-reported anxiety/depression (Wang et al., 2013).

Only one study from the Netherlands looked into educational disparities, and discovered that health literacy partially mediated the relationship between education and self-reported general health (van der Heide et al., 2013).

### **7.3.2 Cancer disparities**

Six studies investigated how health literacy might explain cancer disparities. Three studies looked into the effect of race and health literacy in prostate cancer patients, of which in one, after adjustment, race/ethnicity and health literacy were no longer significant predictors of presentation with advanced stage prostate cancer (Bennett et al., 1998). On the other hand, another study found that health literacy contributed to a reduction of 35% in the association between race and prostate-specific antigen levels (Wolf et al., 2006). With regard to disparities in patient-provider communication in a sample of patients with prostate cancer, Song and colleagues (2014) did not find any significant relationship between race/ethnicity and health literacy; in the final model health literacy was not a significant predictor.

In two studies, education was a more important predictor for information needs in newly diagnosed cancer patients (Matsuyama et al., 2011) and cancer risk information seeking (Hovick, Liang, & Kahlor, 2014) than health literacy. Yet, health literacy was a significant mediator between SES and race/ethnicity on cancer risk knowledge (Hovick et al., 2014).

One study investigated how health literacy might influence disparities in female patients' knowledge about their breast cancer characteristics, and discovered that health literacy did not eliminate most of the racial/ethnic differences under investigation. However, health literacy reduced differences between White and Hispanic women for

being accurately knowledgeable about their breast cancer characteristics (Freedman, Kouri, West, & Keating, 2015).

### **7.3.3 Medication adherence & management**

Health literacy mediated the effect of race/ethnicity on HIV and diabetes medication adherence in two studies. However, they did not find a significant relationship between diabetes-specific and general numeracy on medication adherence (Osborn, Paasche-Orlow, Davis, & Wolf, 2007; Osborn et al., 2011). In another study, the inclusion of health literacy as a predictor reduced the effect of race/ethnicity on understanding of dosage instructions for pediatric liquid medication (Bailey et al., 2009). These results concur with Yin and colleagues (2009) results, where after including health literacy in the final model, neither race/ethnicity, nor education or income predicted the understanding of OTC medication labels.

Yet two other studies discovered that numeracy mediated the effect of race/ethnicity and gender on medication management capacities in HIV patients (Waldrop-Valverde et al., 2009; 2010).

### **7.3.4 Disease control**

One study found that diabetes related numeracy diminished the effect of race/ethnicity on glycemic control to a level of non-significance. Further that health literacy or general numeracy were not significant predictors of glycemic control (Osborn, Cavanaugh, Wallston, White, & Rothman, 2009). Another study demonstrated that health literacy reduced the effect of race/ethnicity in African-Americans and Hispanics on asthma quality of life and asthma control, and for African-Americans only on emergency department visits. However, differences between Afro-Americans and Whites for asthma-related hospitalizations remained (Curtis, Wolf, Weiss, & Grammer, 2012).

Overall only one experimental study looked at the differential effects of race/ethnicity and health literacy. The telephone-based osteoarthritis (OA) self-management support intervention found a significant interaction effect between health literacy and race/ethnicity on change in pain. Non-Whites with low health literacy had

the highest improvement in pain in the intervention group compared to the usual care group (Sperber et al., 2013).

Two studies looked into educational disparities. Whereas in one study health literacy significantly mediated the effect of education on glycemic control (Schillinger, Barton, Karter, Wang, & Adler, 2006), in the other study health literacy reduced only minimally the effect of education on hypertension control but reduced it to non-significance for hypertension knowledge (Pandit et al., 2009).

### **7.3.5 Preventive care**

Three studies investigated the influence of health literacy on cancer screening behavior and knowledge. One study did not find significant racial/ethnic differences with regard to behavioral variables. Yet, after adjusting for health literacy, race/ethnicity was no longer a significant predictor of cervical cancer screening knowledge (Lindau et al., 2002). Another study in Asian Americans found that low health literacy was not significantly associated with meeting colorectal cancer screening guidelines in the Asian group. LEP was a more important predictor, as well as the combination of LEP *and* low health literacy (Sentell, Braun, Davis, & Davis, 2013).

Bennett and colleagues (2009) discovered that health literacy mediated the relationship between education and receipt of a mammography. Also, they found that it mediated the effect of educational disparities on dental care and educational and racial disparities on receipt of influenza vaccine.

One study looked into receipt of vaccinations, in which health literacy reduced the influence of race/ethnicity and education on vaccination receipts only minimally (Howard et al., 2009).

### **7.3.6 End of life decisions**

Three studies investigated the relationship between health literacy and end of life related decisions. One study found that, before an experimental stimulus was introduced to the participants, health literacy reduced the association between race and end-of-life preference to non-significance (Vollandes et al., 2008). On the other hand, in two other

studies, even though health literacy was significantly associated with decisional uncertainty about making an advance treatment decision (Sudore, Schillinger, Knight, & Fried, 2010) or having an advance directive (Waite et al., 2013), it did not significantly reduce the effect of race/ethnicity.

### **7.3.7 Other health outcomes**

Two studies looked into racial/ethnic disparities in the usage of complementary and alternative medicine (CAM), and both found a significant interaction effect between race/ethnicity and health literacy. In both studies, Whites with higher levels of health literacy were more likely to use any kind of CAM. (Bains & Egede, 2011; Gardiner et al., 2013) Gardiner and colleagues (2013) identified the same effect in Hispanics, as well as a higher likelihood to use provider-delivered therapies. This was not the case for the relationship in Afro-Americans.

One study looked into how numeracy was related to direct-to-consumer genetic testing, in which the addition of numeracy to the final model reduced the effect of black race to non-significance. On the other hand, Hispanics did not significantly differ from White participants. There were no significant interactions between race/ethnicity and numeracy (Langford, Resnicow, Roberts, & Zikmund-Fisher, 2012).

Overall, we found only one study that evaluated the relationship between health literacy and physiological outcomes as an indicator of general health status. The study, conducted in an elderly population in Scotland, found that health literacy was linked to worse health outcomes. However, educational and occupational level, as well as cognitive abilities accounted for most of the relationships. Only physical fitness was significantly related to health literacy after adjusting for educational and occupational level and other covariates (Mottus et al., 2014).

Yin and colleagues (2009) investigated how far parents' health literacy mediated the effect of a variety of potential disparities on outcomes relevant to their children. However, after the inclusion of health literacy in the final model, the association of race/ethnicity and health insurance status was no longer significant. As described above,

only understanding of OTC medication labels was significantly associated with parents' below basic health literacy.

Another study compared Spanish- to English-speakers in an emergency department and concluded that the former were less likely to keep up follow-up appointments if they had lower health literacy (Smith, Brice, & Lee, 2012).

## **7.4 Discussion**

In the conceptual literature, health literacy is commonly described as a contributing factor to health disparities but little is known about its actual contribution and potential role in the relationship between social and health disparities. We identified overall 36 studies that sufficiently investigated this relationship. Most of these studies focused on racial/ethnic disparities, followed by some few studies that systematically looked into educational disparities. Only one study specifically investigated the contribution of health literacy on potential gender differences in health. Overall the evidence on the role of health literacy on disparities is still mixed and, for most outcomes, very limited.

Outcomes under investigation and measurements largely varied in the identified studies. There were no evident patterns on whether some measures are more predictive than others in the relationships under investigation. As suggested for clinical settings, measures of functional health literacy, such as the REALM or the S-TOFHLA, had been most frequently used when evaluating the relationship in patients. On the other hand, when investigating the relationship in population-based data, relatively often subjective health literacy measures were rather used.

Some very limited evidence was found on the mediating function of health literacy on self-rated health status when looking into educational disparities. Further, some evidence was identified on the role of health literacy as an independent predictor of health status across different racial/ethnic groups. Independent of health literacy measure, the relationship remained relatively constant. In the case of immigrants, though, language proficiency seemed to be more important in predicting differences in health. There was also some limited evidence of the potential effect of health literacy on

reducing racial/ethnic disparities on medication adherence and understanding of its intake, as well as on knowledge-related outcomes.

With regard to cancer disparities, the included studies yet failed to show any patterns. Four out of six studies did not find health literacy to be a significant predictor in the relationships under investigation. However, one has to take the varying cancer-related outcomes into account that were investigated in these studies.

Given that nearly all studies were conducted in the US, the large focus on racial/ethnic disparities in the identified studies is not surprising. Race/ethnicity is often an assumed proxy for other variables. Whether race is a biological category as such, an indication of socioeconomic status or an independent predictor in which socioeconomic status solely is a mediator, studies on health disparities in the US have largely used race/ethnicity as a predictor of health outcomes (Kawachi, Daniels, & Robinson, 2005).

Even though two independent reviewers rated the quality of most studies as “fair”, there are still some limitations that are inherent to a number of the included studies. From a conceptual perspective, studies often neglected to sufficiently describe the disparity under investigation. General assumptions were made on how health literacy should contribute to disparities but the disparity as such was often only vaguely described. Moreover, descriptions of the disparities under investigation often primarily focused on discussing health literacy as a social determinant of the disparity tested. Even though the conclusion that health literacy might be a determinant per se in this relationship is certainly not wrong, it does not sufficiently take the possible pathways on how health literacy influences health disparities into account. This is also mirrored in the fact that only few studies tested for predefined hypotheses, in which the possible pathways were described. A couple of studies made assumptions about its mediator role, testing for it by using appropriate analysis techniques, including mediation analysis and estimating structural equation models. Other studies tested its potential moderator role and tested, for example, for interaction effects. Still, in most of these studies the potential role of health literacy was not specifically predefined and left a lot of room for interpretation.

Potential pathways might distinguish between social disparities, including race, income or education, and a potential “health literacy disparity” as such (Figure 5), thereby trying to identify not only research gaps but also potential leverage points for interventions that aim at reducing disparities. It is indeed here that the conceptualization and measurement of health literacy might need to move beyond the functional dimension, and instead focus more systematically on other dimensions such as interactive and critical literacy (Nutbeam, 2008). By taking these dimensions into account, one would be able to identify crucial points that are key to, for example, accessing and processing health services and information needed. This also has implications from an interventionist point of view. It would provide clear indications on how and where to increase efforts to reduce health disparities by means of health literacy related interventions, such as providing simplified access to information or support during health-related decision making.

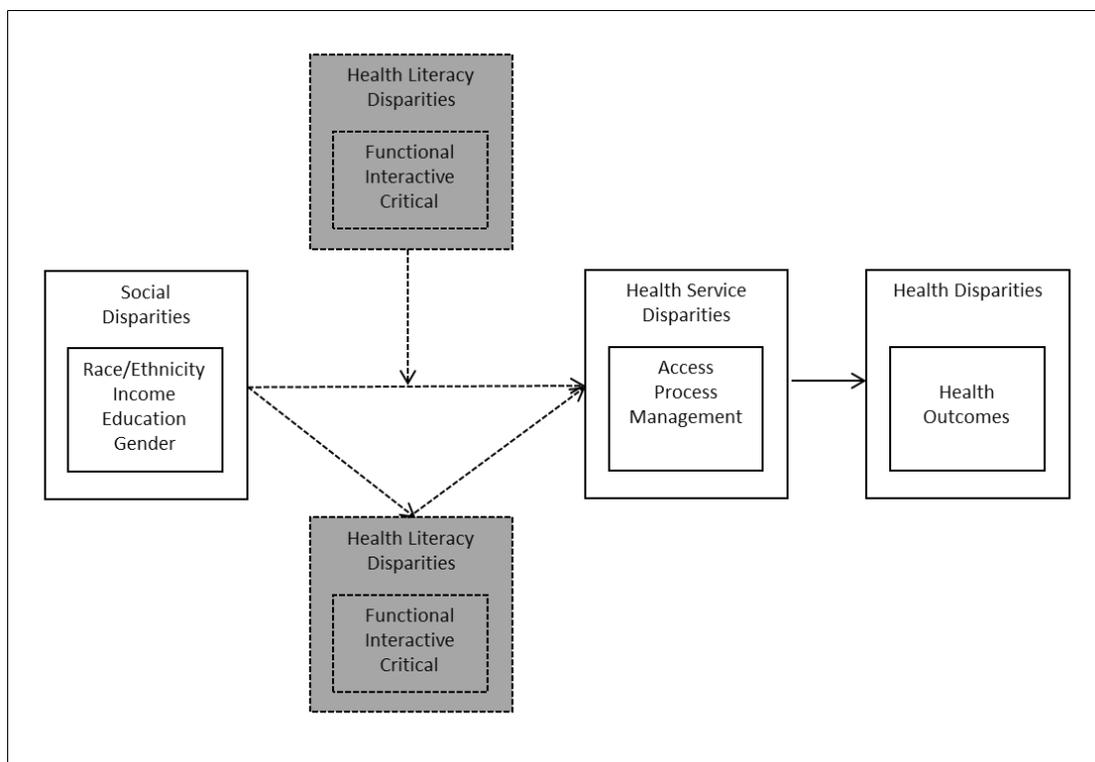


Figure 5: Possible pathways on how health literacy explains disparities in health outcomes

#### **7.4.1 Limitations**

The synthesis presented in this review needs to be carefully evaluated. Studies included in this review used different health literacy measures, cut-off points and analysis techniques, which made comparability sometimes difficult. Further, even though all studies included sufficiently controlled for covariates, there are still inconsistencies between studies. Due to this heterogeneity it was not possible to perform a meta-analysis. Also, despite the attempt to be as comprehensive as possible in the search strategy, some studies might not have been included in this review. Moreover, the search was limited to already published material, thus potentially missing any work that is currently in preparation or under evaluation for publication.

Included in the review were solely studies that explicitly acknowledged the disparity under investigation, therefore ignoring any study that evaluated the relationship between literacy and disparity as a secondary outcome. Future reviews might therefore need to focus on smaller characteristics, such as race/ethnicity or education, to fully grasp the relationships leading to health disparities. In addition, as the field of health literacy is still evolving, consensus on which dimensions should be included when assessing health literacy is still lacking. Therefore, studies that primarily assessed health knowledge, including mental health literacy, were excluded. Only studies that explicitly acknowledged health literacy and included a valid measure of health literacy were included.

#### **7.5 Conclusion**

Evidence on the exact nature of the relationship between health literacy and health disparities remains still scarce. Most studies identified in this review focused on racial/ethnic disparities, being a proxy for other important predictors of health disparities. Some limited evidence was found on the role of health literacy in mediating educational and racial/ethnic disparities with regard to self-reported health status. Also, some evidence was found on its role as a mediator between racial/ethnic disparities and medication management/adherence and health knowledge.

Only few studies tested for hypothesized pathways and systematically scrutinized the relationship between health literacy and health disparities. There is a need to systematically conceptualize the pathways that link health literacy to health disparities and to address whether other social disparities interfere with this relationship. More rigorous studies are needed that not only clearly define the disparity but also the groups under investigation, by choosing an appropriate reference group and potentially holding other social factors constant between these groups.

## **Chapter 8**

### **Does Acculturation narrow the Health Literacy Gap between Immigrants and native-born Swiss?**

*An explorative Study*

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*Abstract*

Research from the US has shown that racial/ethnic minorities are particularly afflicted by limited health literacy and its related negative health outcomes. In Europe, a group that is likely to fall victim of health disparities are immigrants. However, only little research has yet focused on how health literacy might be distributed across different immigrant groups and whether other factors such as acculturation might play a role in this relationship.

The objective of the following study was to compare health literacy levels in three immigrant groups in Switzerland with those of the native population. Further, whether health literacy and variables of acculturation are associated with each other in the three immigrant groups, and if they are independent predictors of self-reported general health status.

646 face-to-face interviews that had been conducted with Swiss natives, or first generation immigrants from Kosovo/Albania, Portugal or Serbia/Bosnia in the Italian-speaking part of Switzerland were analyzed. Functional health literacy was assessed with the Short Test of Functional Health Literacy (S-TOFHLA) in the respective native languages of the different immigrant groups. In addition, health literacy that would be dependent of individual's language proficiency was measured by using three brief health literacy screeners (BHLS) asking about participants confidence in reading and understanding medical information in the language of the host country. Acculturation was further assessed by length of stay and age when taking residency in Switzerland.

Results showed that immigrants had in general lower levels of health literacy. Unadjusted analysis showed that only age when taking residency in Switzerland was significantly associated with the BHLS. In adjusted analysis, the BHLS were significantly associated with self-reported health among Albanian- and Serbian-speakers but not in immigrants from Portugal ( $p \leq .01$ )

The findings of this study suggest that even though people might be health literate in their native language, lack of understanding of medical information in the new host country may lead to worse health outcomes and possibly to disparities in health. In

particular in the clinical setting limited language proficiency might be a significant obstacle to successful disease treatment and prevention.

*Keywords*

*Health Literacy; Immigrants; Acculturation; Language Proficiency*

## 8.1 Introduction

Literacy is usually described as a function of applying reading and writing skills in order to effectively and independently operate in our society. In the field of health, these skills occupy an important place. In an ever-growing information market, the burden on the individual to make informed decisions regarding his/her own health is largely dependent on the correct understanding and evaluation of information (Nutbeam, 2008). Thus, functional *health* literacy and subsequent factors, such as knowledge or judgment, are conditional to appropriate decision-making and understanding of one's own health (Schulz & Nakamoto, 2013).

Health literacy, commonly defined as "*the individuals' capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions*" (Nielsen-Bohlman, Panzer, & Kindig, 2004), has been found to be associated with a variety of health outcomes and behaviors. Limited health literacy has been linked to poorer self-reported physical and mental health (Bennett, Chen, Soroui, & White, 2009; Wolf, Gazmararian, & Baker, 2005), decreased usage of preventive healthcare services and less frequent health promotion behaviors (Scott, Gazmararian, Williams, & Baker, 2002; von Wagner, Knight, Steptie, & Wadle, 2007). In chronically ill patients it has been linked to less disease knowledge (Gazmararian, Williams, Peel, & Baker, 2003) and worse disease outcomes and self-care behavior (Macabasco-O'Connell et al., 2011; Mancuso & Rincon, 2006; Omachi, Sarkar, Yelin, Blanc, & Katz, 2013; Schillinger et al., 2002; Williams, Baker, Parker, & Nurss, 1998). The bottom line of these and similar research results is that health literacy is an important factor in public and individual health and a potential contributor to health disparities.

Research on disparities is concerned with differential states of health between social groups, including health promotion and disease prevention, as well as the treatment and protection of physical or mental state of a person proper. It is primarily concerned with services and benefits being withheld from particular social groups and aims at identifying the causes of these disparities and the underlying mechanisms (Braveman, 2006; Roux, 2012). Disparities may occur due to the unequal distribution of

material resources, health system regulations or prejudice among healthcare providers. Yet, influenced by these social factors, some of the health disparities are rooted in what patients bring to the medical encounter. Among the latter, factors such as knowledge, health-related beliefs and attitudes are to be considered, as well as the factor this study is concerned with, health literacy (Braveman et al., 2011; Egede, 2006).

Most research on health disparities originates in the United States (US), and race/ethnicity has been shown to be the gravest factor in this context, both politically and in terms of research. Research on health literacy has shown that limited health literacy is more frequent among people from racial/ethnic minorities (Kutner et al., 2006). Whether it is under the supposition that health literacy is defined as a social disparity leading to health outcomes or whether the disparity is defined in terms of outcomes and health literacy as the antecedent, studies have shown that health literacy mitigates the effect of commonly found social inequalities leading to health disparities. Studies among African-Americans and Hispanics, for example, have shown that health literacy significantly reduced the influence of race on preventive healthcare knowledge (Lindau et al., 2002), disease management (Curtis, Wolf, Weiss, & Grammer, 2012) or medication adherence (Osborn, Paasche-Orlow, Davis, & Wolf, 2007; Osborn et al., 2011). Even though research is still not exhaustive, the literature largely agrees upon the potential of health literacy as a predictor of health disparities in different racial/ethnic groups in the US.

### **8.1.1 Health literacy among immigrants in Europe**

In many European countries, especially in the wealthier ones in Western Europe, immigrants are often among the most disadvantaged social groups. Part of the explanation lies in the fact that upon arrival in a new country most immigrants initially do not have access to the same legal and social rights as the native population. Especially those that arrive as asylum seekers and refugees are undergoing a particularly stressful transition period and are also more likely to suffer from health consequences, due to traumatizing experiences, as well as constant uncertain living conditions (Bollini & Siem, 1995; Gilgen et al., 2005).

Immigrants are also less likely to be knowledgeable about the regulations and customs of the new host country's health system. This makes immigrants in these countries an important subject for health literacy research to study. The ability to navigate in the healthcare system and to have the relevant skills readily available to do so effectively, is among the core principles of the definition of health literacy (Paasche-Orlow & Wolf, 2007). The lack of these abilities will possibly lead to a deterioration of health. Further, the assumption of lower health literacy levels in immigrants is amplified by cultural as well as language barriers. For immigrants in particular language discordance between the home and the new host country's language might further increase the disparity as such (Asanin & Wilson, 2008).

Another important factor to consider is that health literacy is part of a cultural trend towards more patient autonomy, which in turn is part of the emancipatory ideals that gained currency in Western Europe and North America in the 1960s (Rothman, 2001). No matter whether immigrants come from developing countries in Latin America, Africa or Asia or from the formerly socialist countries in Eastern and Southeastern Europe or from Southern European countries which had authoritarian regimes up to the mid-1970s (Portugal, Spain, Greece), all of these home countries are likely to have been affected less by this emancipatory trend. To put it shortly: many immigrants come from countries where health literacy was less of an ideal than in the country they moved to (Rechel, Kennedy, McKee, & Rechel, 2011).

Compared to the US, knowledge on how health literacy is distributed across different population groups in Europe and especially whether differences occur with regard to health outcomes is still relatively scarce. Even though the last years have seen an increase in research in health literacy, still less than one third of the literature on health literacy has been produced in Europe. (Kondilis, Kiriaze, Athanasoulia, & Falagas, 2008) It was only recently that the European Health Literacy Survey (HL-EU) was launched, which attempted to compare health literacy levels across populations in eight different countries in Europe. However, neither did the survey include immigrant populations from non-EU countries, nor did it attempt to specifically sample participants with a migration background (HLS-EU Consortium, 2012).

Yet, one study in Germany, which attempted to assess diabetes-specific health literacy, found that only 15% of immigrants from Turkey were able to sufficiently describe their disease in their own words (Kofahl, von dem Knesebeck, Hollmann, & Mnich, 2013). Further, a study on refugees in Sweden found that the majority of them had only inadequate or limited health literacy in their respective languages when measured by the HL-EU (Wångdahl, Lytsy, Mårtensson, & Westerling, 2014). Another study in the Netherlands found that among first generation Moroccan Berber speaking women those that were sufficiently health literate reported better health than those that were not sufficiently literate (Bekker, & Lhajoui, 2004).

### **8.1.2 Immigrant health in Switzerland**

In Switzerland, where about 26% of the population aged 15 years and older was born outside of the country (Swiss Federal Statistical Office (SFSO), 2015a), one study found that, among immigrant groups, participants originally from Kosovo had the lowest and Portuguese immigrants the highest knowledge scores on when to seek medical help (Rau, Sakarya, & Abel, 2014). The largest groups of immigrants to Switzerland come from the neighboring countries and are native speakers of one of the official Swiss languages (German, French, Italian, Romansh). Among those coming from countries not sharing one of three official Swiss languages, Portuguese immigrants constitute the largest group. About 253'000 people originally from Portugal are currently living in Switzerland. The second largest group consists of people speaking Serbian as their first language. Nearly 90'000 people from Serbia and about 33'000 from Bosnia and Herzegovina are currently living in Switzerland. Albanian-speakers are the third largest group. The majority of them comes from Kosovo, with around 87'000 people currently residing in Switzerland (SFSO, 2015b).

Already in the 1960s, migrant laborers from Kosovo and Serbia immigrated to Switzerland but legal restrictions implemented in 1992 put immigration to a rather abrupt end. With the beginning of the Bosnian war (1992-1995) and the war in Kosovo (1998-1999), the number of immigrants, this time coming as asylum seekers, increased again (Ruedin, Bader, & Efonayi-Mäder, 2014; Sharani et al., 2010). Labor migrants

from Portugal have mostly immigrated to Switzerland starting in the 1980s, with significant increase once the bilateral agreements between the European Union and Switzerland came into place (Fibbi et al., 2010).

So far studies on these specific immigrant groups and their health behavior and status in Switzerland have provided mixed evidence but patterns start to emerge. A study conducted on behalf of the Swiss Federal Office of Public Health (*Health monitoring of the migrant population (GMM)*) found that in particular Serbians and Kosovars who move to Switzerland are in relatively good physical and psychological health but that this effect diminishes over time, and that immigrants tend to be less healthy than non-immigrants with increasing age (Volken & Rüesch, 2014). The study did not find noteworthy differences with regard to usage of outpatient services between immigrants and non-immigrants. Yet, women from Portugal and Kosovo, as well as men from Serbia and Kosovo, were found to go less often to see a general practitioner. Differences were also evident for preventive healthcare usage (Guggisberg et al., 2011). These results concur with results from other studies which found that women from former Yugoslavia and Portugal were less likely to report that they had received a pap smear test or a clinical breast examination (Bischoff, Greuter, Fontana, & Wanner, 2009; Fontana & Bischoff, 2011). The *GMM* study also found that even though immigrants drank less alcohol, they also tended to eat less vegetables and fruits. In addition, they were often less likely to be physically active and were more frequently overweight (Guggisberg et al., 2011). In particular Kosovars were less likely than Swiss nationals to adhere to recommended fruit and vegetable intake. On the other hand no significant differences were found for Portuguese participants (Guggisberg et al., 2011; Volken, Rüesch, & Guggisberg, 2013). Other studies found similar results. Marques-Vidal and colleagues (2011) found that compared to Swiss nationals immigrants from Portugal and former Yugoslavia had a higher prevalence of being overweight and obese. Also women from Portugal and former Yugoslavia were not as physically active as women from Switzerland (Bischoff & Wanner, 2008; Grossmann, Leventhal, Auer-Böer, Wanner, & Bischoff, 2011).

### 8.1.3 Objective

Given the current scarcity of knowledge on health literacy in immigrants in Europe, this study aimed at assessing health literacy levels in Portuguese-, Serbian-, and Albanian-speaking immigrants in the Italian-speaking part of Switzerland. Further, to compare them to non-immigrants with the assumption that immigrants in general show lower levels of health literacy than the Swiss native population, potentially leading to worse health. In addition, this study assumed that acculturation might be an important factor influencing health literacy levels.

Acculturation describes the adaptation process of an individual to a new environment by adopting beliefs, customs or values of the host country. It has been found to be an important aspect when investigating health disparities (Brown, Consedine, & Maga, 2006; Echeverria, & Carrasquillo, 2006; Lum, & Vanderaa, 2010). Among the determinants of acculturation, the length of time living in a new host country, as well as language proficiency and usage have been most commonly used (Abraído-Lanza et al., 2006).

With regard to literacy and in particular health literacy, it can be plausibly assumed that higher acculturation may lead to higher health literacy levels (Ciampa et al., 2013). Linguistic acculturation for example allows immigrants increased access to health information and healthcare services. It also leads to improvements in other socioeconomic variables, such as education or income, which might influence skills that are relevant to effectively navigate the healthcare system and eventually influence health outcomes (Thomson & Hoffman-Goetz, 2009). Thus, time spent in the new host country might not only influence language skills as such but also literacy and knowledge regarding the healthcare sector. Indeed some studies found that limited language proficiency might mediate the influence of health literacy on health outcomes, meaning that health disparities in immigrants were traced back to low proficiency in the working language of the host country's healthcare system, rather than to health literacy (Omariba & Ng, 2011; Sentell, Braun, Davis, & Davis, 2013). Sentell and Braun (2012), for example, found that in the US participants from different racial/ethnic groups with low English proficiency *and* low health literacy were the most likely to suffer from poor

health. Yet, limited language proficiency was a stronger predictor for health status than health literacy.

The study at hand assumed that those immigrants who lived longer and came at a younger age to the new host country were more likely to perform better on health literacy measures leading to better health status. To sort out the role played by language proficiency as a critical part of acculturation, two different measures of health literacy were compared to each other. One measure was independent of the person's command of the host country's language because it was applied in the person's mother tongue. The other was reflective of the individual's language proficiency because it inquired about problems understanding medical information in the language of the host country that might well be affected by language skills. Thus, speaking of language-independent and language-dependent measures. The assumption was that the effects of acculturation would be stronger when a language-dependent measure was applied and effects found on health status would be stronger when measured with the language-dependent measure:

*H<sub>1</sub>*: Immigrants have lower health literacy than native-born Swiss.

*H<sub>2</sub>*: Immigrants who have been living for a longer time in the new host country have higher levels of health literacy when assessed with a language-dependent measure as compared to a language-independent measure.

*H<sub>3</sub>*: Immigrants who arrived in Switzerland at a younger age are more likely to have higher levels of health literacy when assessed with a language-dependent measure as compared to a language-independent measure.

*H<sub>4</sub>*: Higher health literacy, when measured as a language-dependent variable, will be positively associated with better health status in immigrants.

## **8.2 Methods**

### **8.2.1 Sample & data collection**

The study was part of a larger study on health behavior in three different immigrant populations in Switzerland. Data was collected between October 2014 and March 2015,

and data presented in this study were collected in the Italian-speaking part of Switzerland, namely canton Ticino.

In order to reflect the different immigrant groups in Switzerland appropriately, we included only Serbian-speakers from Serbia and Bosnia, excluding participants from Croatia. For the Albanian-speaking population, we included mostly participants originally from Kosovo, in some cases Albania and Macedonia. Portuguese-speakers were from Portugal only, excluding any participants from other Portuguese-speaking territories. To compare the three groups to non-immigrants, data was also collected among the Italian-speaking Swiss population.

To be eligible to participate in the study, participants had to be over 18 years old, belong to one of the language groups and be resident of the Italian-speaking part of Switzerland. Participants with a migration background had to be born outside of Switzerland (first generation), namely in one of the countries mentioned above, and had to be comfortable enough to fill in the questionnaire in their original mother tongue rather than in Italian.

Student interviewers with the appropriate language backgrounds were trained to conduct face-to-face interviews. Stratified snowball sampling was used and interviewers were asked to exhaust their personal networks in order to reach the populations described. Interviews lasted on average between 25-30 minutes and participants received a CHF10 voucher at the end of the interview.

### **8.2.2 Measures**

Measures that had not yet been adapted and validated in the respective languages and were not publicly available, were translated using forward and back-translation by native speakers. Translations were reviewed and issues were resolved by consensus between the translators and the project coordinators. Measures were subsequently pre-tested and, if necessary, changes were made.

### *Health Literacy*

Functional health literacy was measured by (1) the Short Test of Functional Health Literacy in Adults (S-TOFHLA) (Baker et al., 1999) and (2) the three brief health literacy screeners (BHLS) developed by Chew and colleagues (2004; 2008).

The S-TOFHLA is a short measure of functional health literacy that consists of two parts, a reading-comprehension and a numeracy part. The reading-comprehension part contains 36 cloze-items with four potential options from which participants can choose. Participants have seven minutes to fill in the first part but are not made aware of the fact that they are timed. The numeracy part consists of four items. People are shown four prompts and have to answer four questions about them. There is no time limit.

Each correct answer of the reading-comprehension part is scored with 2 points and each incorrect answer with 0 points, hence creating a score ranging from 0 to 72 points. In the second part each correct answer is scored with 7 points and each incorrect answer with 0 points. The overall S-TOFHLA score ranges from 0 to 100. The conventional classification of the score into inadequate (0 to 53), marginal (54 to 66) and adequate (67 to 100) health literacy was used for illustration purposes in the results section. The S-TOFHLA was administered in the respondent's native language and thus constitutes the language-independent measure.

The three BHLS ask participants about their confidence and capability to read, understand and fill out medical information: (a) "How confident are you filling out medical forms by yourself?"; (b) "How often do you have problems learning about your medical condition because of difficulty understanding written information?"; (c) "How often do you have someone (like a family member, friend, hospital/clinic worker, or caregiver) help you read hospital materials?". Items are scored on a Likert scale from 0 to 4<sup>6</sup> (Chew et al., 2008). Items were averaged to form one single score (BHLS-score).

For the Albanian-, Portuguese- and Serbian-speaking participants the BHLS were slightly changed by asking participants about medical information that would be written in Italian and not in their original mother tongue, with the assumption that

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<sup>6</sup> Scales are ranging from "all of the time" to "none of the time", and "always" to "never"

language proficiency would strongly affect the answer. Therefore, the BHLS are the language dependent-measure of health literacy.

#### *Help-Seeking knowledge*

Rau and colleagues (2014) found significant associations between the groups under investigation and help-seeking health knowledge in Switzerland. To control for this effect, we also included six items that asked about when to seek medical help for common physical health symptoms. Response options were “yes”, “no” or “I do not know”. Each correct answer was scored with 1 point and each incorrect answer and “I do not know” with 0 points. A total sum score was calculated ranging from 0 to 6 points (Guggisberg et al., 2011; Rau et al., 2014).

#### *Acculturation*

In order to test for the proposed hypotheses two determinants of possible acculturation were used: (1.) length of stay in Switzerland in years as a continuous variable and (2.) age when taking residency in Switzerland.

#### *Health Status*

Health status as the dependent variable in the final model was measured with 5 items from the RAND Survey 1.0 (Hays, Sherbourne, & Mazel, 1993). The five items ask about one’s health status in general and in comparison to other people, which are scored on a scale from 0 to 5. The scale score is calculated by averaging the number of all items the participant responded to.

#### *Covariates*

In order to control for potential confounders, data was also collected on age, gender, education and whether participants suffered from any type of chronic condition. We further controlled for where participants had spent most of their school years between the age of 6 and 16.

### **8.2.3 Data analysis**

Data analysis was performed using SPSS Statistics 21 and descriptive statistics were calculated for the different variables. Internal consistency of the health literacy, help-seeking knowledge and health status measures was explored using Cronbach's alpha. Chi-square tests and analyses of variance (ANOVA) were conducted to test for mean differences between the different language groups and appropriate post-hoc tests were conducted.

Multivariate stepwise linear regression analysis was used to investigate the relationship between socio-demographics (Step 1), health literacy (Step 2) and help-seeking knowledge (Step 3) across the different language groups. Both health literacy measures were investigated separately but also included together in the final model. In general, a p-value of  $\leq .05$  was considered statistically significant.

Across all variables, less than 4% of data was missing, indicating that data was missing at random. Therefore listwise deletion was used.

## **8.3 Results**

### **8.3.1 Demographics**

Overall 646 people participated in the study and most of them were Albanian-speaking, followed by Serbian-speaking. Slightly more women than men participated (Table 17). Particularly in the Serbian-speaking group there were significantly more female participants (62.5%,  $p < .001$ ). Most of the participants were in the age range between 45 and 54 years and indicated they had finished secondary or high school. Swiss participants had significantly higher educational levels. Among the immigrant groups, Albanian-speaking participants had the highest educational level, thus confirming findings of the Swiss Federal Office for Migration, which had found that those who immigrated from Kosovo after the mid-eighties had in general higher educational levels (Sharani et al., 2010), whereas Portuguese migrants had lower ones (Fibbi et al., 2010).

Demographic	Total (N=646)		S-TOFHLA Mean		
	n	%	M	SD	p
Age					
18-24	63	9.8	81.79	17.40	
25-34	131	20.3	84.15	18.22	
35-44	120	18.6	79.38	20.28	
45-54	213	33.0	79.83	19.07	
55-64	90	13.9	75.51	21.21	
65 and above	28	4.3	75.61	23.63	<.05
Missing	1	.2			
Gender					
Female	343	53.1	81.98	19.14	
Male	297	46.0	78.03	19.71	<.05
Missing	6	.9			
Education					
no degree/elementary school	112	17.8	70.62	22.40	
secondary school	207	32.0	78.69	19.51	
High school/vocational training	202	32.2	81.92	17.87	
Universities	107	16.6	87.36	16.66	<.01
Missing	18	2.8			
Language					
Albanian	192	29.7	72.82	19.54	
Portuguese	159	24.6	83.14	18.24	
Serbian	168	26.0	77.60	20.64	
Italian	128	19.7	90.08	14.48	<.01
Chronic Condition					
Yes	78	12.1	76.69	20.63	
No	567	87.9	80.49	19.45	>.05
Missing	1	.2			
Total	646	100	80.00	19.62	

**Table 17: Demographics of complete sample, including Swiss participants**

Albanian-speaking participants were on average living for a shorter time in Switzerland than the other two immigrant groups, *Welch's*  $F(2, 322.51) = 7.99, p < .01$ . Serbian-speaking participants had lived in Switzerland on average for 22 years ( $M=22.47, SD=9.52$ ), Portuguese for around 20 years ( $M=20.42, SD=10.59$ ) and Albanian-speakers for about 19 years ( $M=18.79, SD=7.66$ ).

Albanian-speaking participants were also significantly younger when moving to Switzerland,  $F(2, 516) = 7.92, p < .01$ . They were on average 20 years old when they took residency in Switzerland ( $M=20.18, SD=9.90$ ). Serbian-speakers were around 23 years old ( $M=22.80, SD=9.12$ ) and Portuguese 24 years old ( $M=24.09, SD=9.27$ ).

Within the immigrant groups, only 59 participants (11.4%) indicated to have spent most of their school years in Switzerland, of whom Albanian-speakers (57.6%) were the majority.

Only 6% of the immigrants considered Italian as their first language.

### 8.3.2 Health literacy

The reliabilities of the reading comprehension part ( $\alpha=.941$ ), the numeracy part ( $\alpha=.783$ ) and for the overall score ( $\alpha=.892$ ) of the S-TOFHLA were good to very good. For all four languages separately similar results were found, except for the numeracy part of the Portuguese questionnaire, which showed a rather low reliability ( $\alpha=.402$ ). Reliability of the three BHLS was also acceptable ( $\alpha = .776$ ).

As expected, age and education correlated significantly with the overall S-TOFHLA score and the BHLS-score ( $p<.01$ ).

Overall 11.6% of all participants had inadequate health literacy and about the same amount of participants showed to have marginal health literacy. Native born Swiss had, among the four population groups, clearly the highest share of persons with adequate and the lowest share of inadequate health literacy. Among the three immigrant groups, Portuguese showed the highest and the Albanian-speakers the lowest level of health literacy. Table 19 shows the detailed classification of the four population groups into adequate, marginal and inadequate health literacy. Group differences were highly significant ( $\text{Chi}^2 = 47.771$ ,  $\text{df} = 6$ ,  $p<.001$ ), thus supporting  $\mathbf{H}_1$ .

	Albanian	Portuguese	Serbian	Swiss-Italian
Inadequate <i>n</i> , (%)	32 (16.7%)	16 (10.1%)	23 (13.7%)	4 (3.1%)
Marginal <i>n</i> , (%)	40 (20.8%)	10 (6.3%)	21 (12.5%)	5 (3.9%)
Adequate <i>n</i> , (%)	120 (62.5%)	133 (83.6%)	124 (73.8%)	118 (92.9%)

**Table 18: S-TOFHLA Health Literacy Levels**

To further test  $\mathbf{H}_1$ , ANOVAs were conducted to compare average scores on the S-TOFHLA and the BHLS between the different language groups. Albanian-speakers

had again significantly lower scores than Portuguese and Swiss participants. For the reading comprehension part only, similar differences were found.

In the numeracy part Swiss participants had significantly higher scores than Albanian-speaking and Serbian-speaking participants (Table 19).

	Albanian		Portuguese		Serbian		Swiss-Italian		Welch's F	p
	M	SD	M	SD	M	SD	M	SD		
Overall S-TOFHLA Score	72.82 <sup>a</sup>	19.542	83.14 <sup>b</sup>	18.24	77.60 <sup>a,b</sup>	20.64	90.08 <sup>d</sup>	14.48	29.812	<i>p</i> <.000
Reading Comprehension	51.64 <sup>a</sup>	15.91	59.50 <sup>b</sup>	15.35	55.64 <sup>a,b</sup>	15.39	65.50 <sup>d</sup>	10.23	33.358	<i>p</i> <.000
Numeracy	21.18 <sup>a</sup>	9.83	23.64 <sup>b,c</sup>	6.03	21.96 <sup>a,b</sup>	9.25	24.58 <sup>c</sup>	8.51	5.355	<i>p</i> <.002
BHLS-score	2.54	0.97	2.70	0.88	2.64	0.82	2.80	0.69	2.582	<i>p</i> =.06

**Table 19: Means in S-TOFHLA and Chew et al. screening question scores for language groups df 3, 351.51 (Overall S-TOFHLA Score); df 3, 353.72 (Reading Comprehension); df 3, 344.58 (Numeracy); df 3, 350,553 (BHLS-score)**

<sup>a,b,c</sup> Same superscript letter= no significant differences; Based on Games Howell Posthoc Tests.

When health literacy was assessed with the BHLS, the average score just missed the conventional significance level. Some interesting observations, however, were made for the individual items. In general most of the study participants indicated to be “quite a bit” confident (36.7%) in filling out medical forms on their own. Portuguese participants had the significantly lowest mean, *Welch's F*(3, 343.80) = 7.47, *p*<.01.

Furthermore, most of the participants (34.5%) indicated to have problems learning about a medical condition because of difficulties understanding written information “some of the time”. Interestingly, the Portuguese scored significantly higher on this question than the Albanian-speaking or Serbian-speaking participants, *Welch's F*(3, 349.89) = 4.26, *p*<.01. Similar results were found for the third question on whether they needed help from a family member or health professional to read medical information. Portuguese and Swiss participants scored significantly higher than Albanian- or Serbian-speaking participants, *Welch's F*(3, 348.12) = 8.44, *p*<.01. In summary, **H<sub>1</sub>** received strong support. Overall, immigrants to Ticino from Kosovo/Albania, Portugal and Serbia/Bosnia showed lower levels of health literacy than native-born Swiss.

Table 20 indicates that **H<sub>3</sub>** receives strong support. Immigrants who had arrived at a younger age in Switzerland performed better on the language-dependent measure (BHLS). Length of stay, the other independent variable, clearly did not have the hypothesized effect (**H<sub>2</sub>**). For the Serbian immigrants, the opposite effect even reached significance.

Health Literacy	Immigration Variable	Albanian	Portuguese	Serbian
Overall S-TOFHLA score	Length of residency	-.112	-.024	.284***
	Age at immigration	-.046	-.106	-.093
Average score screening questions	Length of residency	.065	.073	.044
	Age at immigration	-.464***	-.263**	-.345***

**Table 20: Health literacy as a function of “length of residency in Switzerland” and “Age at arrival in Switzerland”.**  
**Numbers shown are standardized beta coefficients from linear regressions without controls**

### 8.3.3 Help-Seeking Knowledge

Most participants answered three out of six questions correctly ( $M=3.52, SD=1.20$ ) when asked about when to seek for medical help. Knowledge correlated significantly with all health literacy measures ( $p<.05$ ).

Compared to the other language groups, Albanian-speaking participants were significantly less likely to answer correctly. Swiss participants had overall the highest scores, *Welch’s F*(3, 339.63) = 23.90,  $p<.01$ .

Within the immigrant groups, in unadjusted analysis neither age at immigration nor length of residency in Switzerland were significantly associated with help-seeking knowledge.

### 8.3.4 Health status

The scale showed good internal reliability (Cronbach’s  $\alpha=.731$ ). Scores were calculated based on a summative score that was averaged by the number of items (Min=0, Max=100). The mean was 63.33 ( $SD=17.54$ ). No significant differences in general health status were found between the language groups.

Bivariate analysis showed that general health status correlated significantly with age, education and presence of a chronic condition ( $p < .01$ ). It was also significantly correlated with the overall S-TOFHLA score and the BHLS-score ( $p < .01$ ).

In unadjusted regression analysis, length of residency in Switzerland, as well as age at immigration was significantly associated with health status in immigrants. However, once controlled for age, these associations were no longer significant.

### 8.3.5 Health literacy and general health status

The overall S-TOFHLA score was added as a continuous variable to the regression model. Unadjusted regression analysis showed that in the overall population the score was significantly associated with general health status ( $\beta = .197$ ,  $t(643) = 5.08$ ,  $p = .000$ ). The relationship was also significant when adjusting for demographics. Age, education and presence of a chronic condition, as well as being Albanian-speaking and help-seeking knowledge were significantly associated with general health status.

Unadjusted analysis showed that also the BHLS-score was significantly associated with health status ( $\beta = .343$ ,  $t(642) = 9.26$ ,  $p = .000$ ). The association remained also significant after adjusting for demographics and help-seeking knowledge.

Additional analysis when aggregating the immigrant groups into one group showed similar results, but help-seeking knowledge did not remain significant. Length of time living in the country and age upon arrival in Switzerland were not significantly associated with health status in the model.

In order to test **H<sub>4</sub>**, separate analyses for the three immigrant groups separately were conducted. As depicted in Table 21, the S-TOFHLA, being the language-independent measure, was not significantly associated with health status. Instead the BHLS-score was significantly associated with health status in the Albanian- and Serbian-speaking groups. Therefore partially confirming **H<sub>4</sub>**. However, in the Portuguese group only help-seeking knowledge was significantly associated with health status. Age at immigration to Switzerland was only significantly associated with health status in the Serbian group. The addition of the BHLS-score to the final model in the Serbian-speaking group reduced the initial significant effect of length of stay to non-significance.

In the other two immigrant groups, however, length of residency in Switzerland was not significantly associated with health status.

	Albanian (n=191)	Portuguese (n=151)	Serbian (n=160)
	Final Model ( $r^2_{\text{adju}}=.343$ )	Final Model ( $r^2_{\text{adju}}=.151$ )	Final Model ( $r^2_{\text{adju}}=.310$ )
	$\beta$	$\beta$	$\beta$
Age	-.359	.260	<b>-1.006**</b>
Education	-.071	.120	.092
<i>No Chronic Disease (reference)</i>			
Chronic Disease	<b>-.277**</b>	<b>-.216**</b>	<b>-.171*</b>
<i>Male (reference)</i>			
Gender	<b>-.162**</b>	-.068	-.024
<i>Most school years spent outside of CH (reference)</i>			
Most school years spent in CH	.117	-.008	-.120
Length of time living in CH	-.030	-.329	.468
Age when arriving in CH	.266	-.337	<b>.604*</b>
Overall STOFHLA score	.007	.129	.083
Average score screening questions	<b>.388**</b>	.026	<b>.281**</b>
Help Seeking Knowledge	.025	<b>.231**</b>	.020

**Table 21: Stepwise multiple linear regression.**  
**Health literacy and help seeking knowledge as a function of general health status; \*\*  $\leq .01$  \* $\leq .05$**

## 8.4 Discussion and conclusion

The current study sought to investigate the hypotheses that health literacy varies according to acculturation among different immigrant groups and that immigrants will have in general lower health literacy levels than the native population. Further, that health literacy when measured, as a language-dependent variable will be predictive of health status.

The study did not confirm results found by previous studies conducted in immigrant populations in Switzerland. Even though immigrants were not healthier (indeed the means for the immigrant groups were slightly lower than for the Swiss population), no significant differences between the Swiss population and the immigrant groups with regard to self-reported health status were found. Results of this study point

partially towards what has been described as the “healthy immigrant effect” (Acevedo-Garcia et al., 2010), meaning that those who decide to immigrate are often healthier than their counterparts at home, respectively at the new host country. Still, due to acculturation, these effects may wear off and immigrants are more likely to adopt health behaviors and norms found in the host country (Acevedo-Garcia et al., 2010).

In this study, language-independent health literacy was measured using the S-TOFHLA, meaning that participants were asked to fill it in in their native language. Language-dependent health literacy on the other hand was measured using the BHLS, asking participants about their confidence and capabilities to understand medical information written in Italian language.

Results of the study confirmed the first hypothesis (**H<sub>1</sub>**). Participants with a migration background had significantly lower levels of health literacy when measured with the S-TOFHLA but surprisingly not when measured with the BHLS. Albanian-speaking participants had consistently the lowest scores, even though they had overall the highest educational level. These results concur with Rau and colleagues’ (2014) findings, which showed that Kosovars in Switzerland had in general the lowest scores for help-seeking health knowledge. Results are also reflective of what Toci and colleagues (2014) found in their study on functional health literacy in Kosovo. One out of five people in their study had marginal or inadequate health literacy and rates were comparably low compared to results found in the neighboring country Serbia. On the other hand, we also found that Portuguese compared to the other immigrant groups had in general the highest levels of health literacy, even though they had the lowest educational level.

Unadjusted analysis showed that age at immigration to Switzerland was significantly associated with language-dependent health literacy, thus partially confirming **H<sub>3</sub>**. Participants who immigrated to Switzerland at a younger age performed better on the language-dependent health literacy measure than those who immigrated at a later age. However, length of residency in Switzerland was not significantly associated with neither of the measures. Only in the Serbian-speaking group one significant

association between length of stay and language-independent measure was found but the effect found was in the reversed direction. Thus, **H<sub>2</sub>** was not confirmed.

**H<sub>4</sub>** speculated that language-dependent health literacy as measured by the BHLS would be more predictive of health status in the immigrant groups. This hypothesis was partly confirmed. It was found that in the Albanian-, as well as in the Serbian-speaking group these items remained significantly associated with health status when controlled for other confounders. However, in the Portuguese group no association was found.

Results of this study might indicate that when immigrating to a new country, people do not necessarily “carry” with them their health literacy to the new home country, which in turn might influence health status. Instead language and specifically language barriers may become more important and eventually prevent people from searching and receiving appropriate healthcare, whether preventive or acute. These results are in line with those identified by Sentell and colleagues (2012; 2013), who found that language proficiency was even more important than health literacy in predicting health status. Other studies have shown that less proficiency in the language of the host country leads for example to worse self-reported health (Mui, Kang, Kang, & Domanski, 2007; Pottie, Ng, Spitzer, Mohammed, & Glazier, 2008) and less usage of healthcare services (Derose & Baker, 2000; Lebrun, 2012). Still, for Portuguese participants the BHLS were not predictive of health status but of help-seeking knowledge instead. Part of the explanation might lie in the fact that the Portuguese language is much closer to the Italian than the other two languages and thus reading and understanding of medical information is likely to be easier for Portuguese. Therefore, knowledge on when to seek medical help might be a more important predictor in this group.

Neither length of residency nor age when immigrating to Switzerland was predictive of health status. Indeed, a large proportion of participants with a migration background indicated to have been living already 21 to 30 years in Switzerland, thus possibly minimizing the potential contribution of it on health status. Still, findings might be indicative of the fact that even if people have spent considerable time of their life in the host country, possible segregation and homogenous social networks with regard to

ethnicity (Wimmer, 2004) might have prevented language acquirement. Thus, having potentially precluded them from acquiring skills important to navigate the healthcare system in the host country (Goodman et al., 2012; Zanchetta, & Poureslamial, 2006).

#### **8.4.1 Limitations**

There are several limitations to this study. Firstly, due to the recruitment strategies used it cannot be excluded that people who already had lower levels of functional health literacy refused to participate in the study. Secondly, because of using snowball sampling participants might have come from socially cohesive groups, thus not making it representative of the population groups at large. Further, the study did not include a measure of language proficiency as such, which would have allowed to test for the validity of the language-dependent measure and to explore whether it would have explained some of the variance found.

#### **8.4.2 Implications**

This study has important implications for healthcare practitioners and researchers. Nearly 9% of the population in Switzerland speaks one of the investigated non-official languages (SFSO, 2015c) and even though people might be health literate in their own language, lack of awareness regarding one's rights and expectations by the healthcare system towards them, may eventually lead to worse health outcomes and disparities (Singleton & Krause, 2009). Particularly in the clinical setting, limited language proficiency might be a significant obstacle to successful treatment and prevention.

Sudore and colleagues (2009) found for example that language discordance between patient and healthcare provider, independently of health literacy levels, prevents effective doctor-patient communication. Also in Switzerland where healthcare is largely general practitioner centered, physicians have to decide on their own whether they deem it necessary to provide information other than in the official languages and if they want to adjust to any language discordance.

Further research is still needed to understand the interplay between health literacy, acculturation (including language proficiency and length of stay) and potentially

emerging health disparities. Particularly longitudinal studies investigating comparable groups in the country of origin and the country of migration might shed light on these potential relationships.

## **Chapter 9**

### **Conclusion**

*Sarah Mantwill*

## Conclusion

Discussions on health literacy have moved far beyond its initial definition as being solely the capability to apply reading and writing skills in the medical environment. The core of this research tradition has moved from “*Does the patient understand?*” to questions such as “*Are we aware that the patient does not understand?*”, “*What does he/she understand?*” and “*How do we make him/her understand?*”. Healthcare practitioners, as well as researchers, have recognized the need to investigate the link between low literacy and potential health outcomes in order to understand how to ideally intervene on this relationship. However, definitional and conceptual issues that persist until today have made it difficult to sufficiently operationalize the term health literacy.

On the other hand, practical suggestions on how to potentially overcome barriers due to limited health literacy have been described. Recommendations, such as simplifying health information or providing access to sufficient information, have been suggested as answers on how to circumvent the potential dangers of limited health literacy. Nevertheless, the lack of common agreement on what health literacy should exactly entail and how to appropriately assess it, has often prevented more systematic investigations on health literacy and its potential as an intervenable factor that go beyond these practical recommendations.

Most of the research on health literacy originates in the US. This does not come as a surprise, given that research on differences in health have been persistently linked to differences in racial/ethnic groups in the US (Williams & Collins, 1995). Health literacy as a potential explanatory variable in explaining differences in health lends itself as a possible remedy to disentangle racial/ethnic disparities from, for example, educational disparities. However, this was a phenomenon less known to European countries and only recently interest on health literacy and its value in explaining differences in health has gained attention also in Europe.

This work aimed at contributing to the current conceptual discussion on health literacy by investigating the concept of health literacy from three different perspectives. In a first step, an attempt was made to operationalize and eventually measure health literacy in countries that do not yet have systematically integrated health literacy as a

research topic into their healthcare agendas. In a second step the relationship between functional health literacy and healthcare costs was explored with the aim to (1.) understand whether relationships found in the US would hold true and (2.) contribute to the still relatively little evidence available on this relationship. The last step moved beyond solely empirical evidence and provided a conceptual discussion on how health literacy is a potential contributor to health disparities and delineated potential pathways and differences in outcomes due to differential assessments of this relationship.

### **9.1 Main results and implications**

The first part of this dissertation described the adaptation and translation process of a commonly used health literacy measure into four different languages, namely German, French, Italian and Mandarin Chinese to be used in Switzerland and the PR China. Even though these countries could not be further apart, whether culturally or linguistically, the studies presented were able to show that health literacy, as operationalized by a short test of functional health literacy, might show sufficient validity also in other countries than the US. Both measures showed high internal reliability and were related to many of the commonly associated predictors of health literacy. Yet, both studies also revealed that certain parts still need further refinement and that relationships need to be further investigated. Particular in the German-speaking part of Switzerland - even though in line with a relatively high educational level - the overall measure seemed to be too simple for this specific population. In contrast, it was found that in the Italian-speaking part of Switzerland, as well as in the PR China, the measure was sufficiently able to distinguish between three different levels of health literacy. Further sensitivity analyses across the different populations is needed to sufficiently understand in how far measures are able to detect different levels of health literacy.

Having established a potential cross-cultural validity of the concept of health literacy and its measurement, the second part presented findings on the relationship between functional health literacy and healthcare costs in a sample of diabetes patients in Switzerland. The studies identified a significant relationship between health literacy, as measured by one of the Brief Health Literacy Screeners (Chew et al., 2008), and

healthcare costs over the range of two years. Lower health literacy was associated with higher total costs and higher outpatient costs, as well as medication costs. The studies did not only confirm findings from the US but also provided further evidence on a still understudied relationship. The studies were the first to track a relationship of costs in a country where nearly all of its population is covered by obligatory health insurance and where treatment is less likely to be forgone for financial reasons, therefore providing a more comprehensive picture. The association of health literacy with costs is not only reflective of the contribution of health literacy to financial outcomes as such but also provides evidence on the potential overuse of healthcare services by people with lower levels of health literacy. In contrast to the US (Hardie, Kyanko, Busch, LoSasso, & Levin, 2011) it was found that in Switzerland lower health literacy was significantly associated with higher outpatient costs and higher physician visits but not with increased emergency department and inpatient admission costs. However, these results are not completely contradictory to the relationships found in the US, given that Switzerland has a healthcare system that is largely general practitioner centred. Therefore people will often first seek help from their general practitioner before going to the hospital or an emergency department. With regard to the relationship found for medication costs, results not only have implications for the system at large but also the individual level. In the case of diabetes patients, accurate medication intake and management is among the key concerns for effective treatment. Explanations on why patients with lower levels of health literacy have higher medication costs are manifold but one explanation might be that patients do not sufficiently communicate prior prescribed medications and that general practitioners might not sufficiently elucidate on prior or other ongoing medication regimen. Some explanations might be also found in the fact that diabetes patients with lower health literacy levels are less likely to adhere to their medication regimen (Osborn et al., 2011), potentially leading in the long run to increased medication costs, thus creating a revolving-door effect.

The third part of this work focused on the conceptual discussion on how health literacy is linked to health outcomes, specifically those differences in health that are linked to social disparities. In a first step, a conceptual discussion was presented that

aimed at discussing current challenges in advancing research on this particular relationship and issues that might have prevented health literacy to be more systemically explored as a factor that might affect common health disparities. The core of the discussion revolved around the lack of conceptual clarity of the term health literacy, the potential pitfalls of the measures that are currently used to assess health literacy and its implications for research on health disparities, as well as its potential understanding as a factor to be systematically integrated into interventions that aim at reducing disparities. The discussion further outlined potential pathways on how health literacy might contribute to disparities. Whether health literacy is an independent factor, mediator or moderator in the relationship, its differential effects will have different implications for research and interventions. The discussion finished with suggestions on how to potentially improve research on the role of health literacy in creating disparities in health. When investigating the role of health literacy in this relationship, conceptualizations and measurements should take the particular health disparity under investigation sufficiently into account. This includes the sound choice of reference groups, which show patterns of the expected health outcome and eventually disparity. Further, each possible pathway that describes health literacy as a factor linking social disparities to differences in health should be given sufficient consideration and should be put to the test. Health literacy measures should be reflective of the disparity under investigation and measures should be equally and consistently applied across comparison groups. In terms of interventions aimed at reducing health disparities commonly cited recommendations to overcome challenges - that are likely to occur due to limited health literacy - should be given appropriate consideration. Thus, accommodating not only populations with in general higher levels of health literacy but also including populations that have in general lower levels. Technologies might provide new opportunities but need to be carefully evaluated by taking the needs and skills of those with limited health literacy into account.

In addition, a systematic review was presented that aimed at understanding in how far health literacy as a potential contributing factor to health disparities had been already investigated in the empirical literature so far. The review identified only little

evidence that would conclusively explain the potential explanatory power of health literacy on disparities. Some evidence was found on a potential mediator role of health literacy in creating differences in self-reported health with regard to educational disparities. Further, that health literacy might be a moderator in explaining differences in medication adherence and management with regard to racial/ethnic differences. Overall, the review showed that only few studies have yet explicitly described and tested the pathways on how health literacy potentially contributes to differences in health that are often linked to social disparities. More systematic hypotheses testing is still needed, as well as a more theoretical approach to comprehensively explain the role of health literacy.

In a final step, based on data drawn from a sample collected in the immigrant population in the Italian-speaking part of Switzerland, the potential influence of health literacy and its relationship with acculturation, as described by language proficiency, length of stay and age upon arrival in the host country, on health was analysed. analysis showed that language-dependent health literacy, as measured by asking whether one would be comfortable reading and understanding health information in the language of the host country, was more predictive of health status than health literacy assessed by a measure written in one`s mother tongue. This effect also remained when controlling for other factors, such as length of stay or age when arriving in the new country. However, age when arriving in Switzerland was significantly associated with understanding of medical information in the host country`s language, thus suggesting a potential mediation effect. In line with similar findings (Derose & Baker, 2000; Lebrun, 2012; Sentell & Braun, 2012; Sentell, Braun, Davis, & Davis, 2013) results of this study showed that among immigrant populations understanding medical information written in the language of the host country might be a significant barrier to receiving appropriate care and treatment in the new country, as indicated by lower health status.

In conclusion, the work presented in this dissertation was able to show that a measure of health literacy that was originally developed in the US can be sufficiently adapted and validated to be used in other countries. Therefore, showing that the underlying construct might be applicable to other contexts than the US. Further, the

thesis showed that also assumed relationships were found to hold true in a different context other than the US. Moreover, by looking into healthcare costs in particular, this dissertation explored a still highly under-investigated relationship. This evidence is particularly relevant to health policy makers and decision makers in health in general. Showing that lower levels of health literacy contribute to higher healthcare costs, is an important factor when trying to push “health literacy” as a relevant topic up the policy agenda.

For policy makers equally important, as well as to researchers and practitioners, is to better understand the link of how health literacy contributes to differences in health that have been normally attributed to social disparities, such as race/ethnicity or education. The thesis showed that, however, little systematic evidence is yet available and current research on the topic might want to adapt more systematic approaches in order to sufficiently investigate the relationship and to exclude differential effects of other relevant variables.

## **9.2 Implications and suggestions for future research**

One of the most important parts of this dissertation has focused on elucidating the link between health literacy and disparities in health. Results show that little is known yet about the interaction of social disparities and health literacy on potential health outcomes. From an interventionist point of view this leaves a lot of questions open. In particular the question on how to intervene on a factor of which we do not yet understand its exact linkages with other factors.

As already outlined in the corresponding chapters, interventionist might want to localize potential intervention points that would go beyond the concept of health literacy as a solely functional ability. In order to understand how to potentially leverage a factor such as health literacy in reducing disparities, researchers need to examine other factors than individual skills. Thus, suggesting an ecological approach to the study of this relationship.

So far research on health literacy has largely treated it as an individual factor, detached from personal networks and social environments at large (Lee, Arozullah, &

Cho, 2004). It might be of particular interest to understand in how far limited health literacy might be influenced by social support and how higher health literacy levels of people being close to the individual might compensate for lower individual health literacy.

Only few studies yet have looked into the relationship how, for example, social support might contribute to different health outcomes when taking health literacy into consideration and results are far from being conclusive (Osborn, Bains, & Egede, 2010; Lee, Gazmararian, & Arozullah, 2006; Lee, Arozullah, Cho, Crittenden, & Vicencio, 2009). Two studies for example found, contrary to what one would have expected, that social support did not buffer the effect of low health literacy on health outcomes, but instead had a positive impact on people with already higher health literacy levels (Johnson, Jacobson, Gazmararian, & Blake, 2010; Lee et al., 2009).

Other studies have investigated in how far health literacy is associated with community characteristics and found that for example racial composition of prior neighborhood would influence health literacy, meaning that for instance growing up in a largely white community would be associated with higher health literacy levels (Kaphingst, Goodman, Pyke, Stafford, & Lachance, 2012; Sentell, Zhang, Davis, Baker, & Braun, 2014).

Even though functional health literacy skills are often assumed to be stable characteristics, other dimensions of health literacy, such as communicative health literacy (Nutbeam, 2000) or declarative and procedural knowledge (Schulz & Nakamoto, 2013), are likely to be influenced by different experiences and information, which are potentially shaped by one's individual social environment (Rubinelli, Schulz, & Nakamoto, 2009). It might be well the case that resource-richer environments for example would lead to increased information seeking skills and knowledge in individuals (Berkman & Glas, 2000), eventually translating into increased health literacy. Little is known yet on this dynamic interplay between social environment and health literacy and how underlying communication patterns might shape this relationship, eventually leading to differences in health outcomes that otherwise would be related to social disparities. Some evidence points towards the fact that those having higher health

literacy levels act as advice givers whereas those that have lower levels of health literacy prefer to remain at the receiving end (Ellis, Mullan, Worsley, & Pai, 2012; Edwards, Wood, Davies, & Edwards, 2013).

Understanding these underlying communication patterns on how individuals with different levels of health literacy share information and are respectively influenced by it, would allow to adequately respond to limited health literacy by means of communication interventions. Further, understanding which message features are more likely to be shared and processed among different groups of different health literacy levels might shed light on message design. Therefore, further research should also explore how differences in message processing are shaped by different levels of health literacy.

Most of the research so far, has mostly focused on written health information and only very recently researchers started to look into how health literacy interacts with different message features (Meppelin, van Weert, Haven, & Smit, 2015; Vosbergen et al., 2014). Models on dual processing might shed light on this relationship by identifying how individual processing capacities, as described by different health literacy levels, might influence health information seeking and sharing.

The Elaboration Likelihood Model (ELM) for example is a potentially useful framework to explore how people with different levels of health literacy might process messages relevant to health. The ELM describes how information might be processed by using two different routes. The central route refers to the active processing of a message. People assess the message by weighing and elaborating the specific arguments of the message in relation to already existing knowledge. They will be eventually persuaded, for instance, to engage in a certain target behavior if the arguments are deemed convincing enough. On the other hand, the peripheral route is used when people are less engaged by the content of the message or lack the ability to appropriately process the message. However, these people might be still persuaded by simple cues of a message without scrutinizing the strength of the argument for example. Instead they will rely on other cues or cognitive heuristics, such as attractiveness of the message in general or source credibility (Petty & Brinol, 2010).

Central to the ELM is that people have the motivation and ability to elaborate the message (Rucker & Petty, 2006). Ability, which might be defined as having sufficient health literacy when reading a message relevant to one's health, is likely to influence elaboration using the central route. In the case of a health message for example, an individual who is able to process the information is likely to have the relevant health knowledge to understand the arguments communicated in the message. Other factors, such as need of cognition will further influence motivation to engage with the message content (Petty & Cacioppo, 1986; Rucker & Petty, 2006).

People with higher need of cognition for example have been found to be more likely to use the central route as compared to those with lower need of cognition (Petty & Jarvis, 1996). Studies have found that need for cognition is indeed correlated with many of the variables that are also correlated with health literacy, such as education (Davis, Severy, Kraus, & Whitaker, 1993; Petty, & Jarvis, 1996), age (Spotts, 1994; de Bruin, McNair, Taylor, Summers, & Strough, 2015) and more specifically, for instance, health information recall (Reid et al., 1995). Further, studies from marketing have shown that consumers who are illiterate are more likely to be persuaded by peripheral cues (Jae & DelVecchio, 2004; Viswanathan, Rosa, & Harris, 2005).

By investigating how health literacy is influenced by one's social environment and how information might be sought and shared within these settings, as well as understanding which message features are more likely to be processed and eventually shared in these environments, research might be able to respond to the increasing need for population-based interventions in the field of health literacy. Further, by elucidating theoretically how to optimize health messages for different groups this approach might add to the discussion on how to overcome certain types of communication inequalities in health. Thus, contributing to the field of health communication at large.

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## **Appendix**

The Role of Health Literacy in  
Explaining Health Disparities  
*A Systematic Review*

7 Tables – Data Extraction (36 Articles)

### Self-Reported Health Status

First Author	Design	Participants	Country	Instrument Cut off points	Sample	Outcomes assessed	Associations	Quality
<b>Race/Ethnicity</b>								
Lee 2015	Cross-sectional	<b>White: 91%</b> <b>Asian American Immigrants: 9%</b> (Chinese (3%), Koreans (2%), Filipinos (2%), South Asians (1%), Vietnamese (1%))	USA	English, Spanish, Chinese (Mandarin, Cantonese), Korean, and Vietnamese: two <b>subjective proxy measures of health literacy</b> : continuous.	2007 California Health Interview Survey (CHIS) (N= 33,668)	<b>Health status</b>  <b>Symptoms of depression</b>	HL was associated with health status and depression symptoms among Whites and aggregated Asian immigrants groups ( $p<.01$ ). In Chinese and Koreans HL was a predictor of self-rated health status ( $p<.05$ ). In Koreans and South Asians HL was a sig. predictor of depression symptoms ( $p<.05$ ).	F
Omariba 2011	Cross-sectional	<b>Non-immigrants: 83%</b> (second generation Canadians: 14.8%)  <b>Immigrants: 17%</b> (established European or American: 33.1%, established from other countries: 42.6%; recent European or American: 4.6%; recent from other countries: 19.7%),	Canada	English & French <b>Health Activities Literacy Scale</b> (HALS) (191 items): low vs. high	Participants $\geq 16$ International Adult Literacy and Skills Survey (IALSS) (N=22,818)	<b>Health status</b>	Among immigrants the effect of HL on good self-rated health was reduced to n.sig. by discordance between mother tongue and language of survey administration (OR 0.65; 95% CI, 0.45-0.95).	F
Omariba 2014	Cross-sectional	<b>First: 17%</b> <b>Second: 12%</b> <b>Third-plus generation immigrants and non-immigrants : 71%</b>	Canada	English & French <b>Health Activities Literacy Scale</b> (HALS) (191 items): low vs. high	Participants $\geq 16$ International Adult Literacy and Skills Survey (IALSS) (N=22,818)	<b>Disability</b>	HL was n.sig. associated with self-reported disability among different immigrant groups. Among different generations of immigrants a sig. association was found but education, income and employment reduced its effect to n.sig.	F
Sentell 2011	Cross-sectional	<b>White: 34%</b> <b>Japanese: 24.5%</b> <b>Filipino: 14.2%</b> <b>Native Hawaiians: 15.7%</b> <b>other AA/PI</b> (Asian Americans/Pacific Islanders): <b>11.6%</b>	USA	English & Spanish <b>Single Health Literacy Screener<sup>1</sup></b> : low vs. adequate	2008 Hawai'i Health Survey (HHS) (N=4,399)	<b>Health status</b>  <b>Depression</b>  <b>Diabetes</b>  <b>BMI</b>	Low HL was associated with poor health status in Japanese, Filipinos, other AA/PI and Whites; with diabetes in Hawaiians and Japanese; and with depression in Hawaiians ( $p<.05$ ). No sig. relationship between HL and being overweight was found.	F

Sentell 2012	Cross-sectional	<b>White:</b> 49% (<1% LEP) <b>Vietnamese:</b> 1.5 (38.5% LEP <sup>2</sup> ) <b>Korean:</b> 1.2% (39.3% LEP) <b>Chinese:</b> 3.5% (27.4% LEP) <b>Latino:</b> 21.6% (37.3% LEP) <b>Other ethnicity:</b> 23.1% (15.2% LEP),	USA	English, Spanish, Chinese (Mandarin, Cantonese), Korean, and Vietnamese: <b>two subjective proxy measures of health literacy:</b> continuous	2007 California Health Interview Survey (CHIS) (N= 48,427)	<b>Health status</b>	Low HL was only sig. associated with poor health status in White and “other” participants ( $p<.05$ ). LEP was a more important predictor of poor health status in Latinos, Vietnamese, and Whites. Highest odds of poor health status when low health literacy and low English proficiency combined in Latino, Chinese, Vietnamese and Others.	F
Wang 2013	Cross-sectional	<b>Hui minority:</b> 57.5% <b>Han ethnicity :</b> 42.5%	China	Chinese HL instruments based on revisions of the <b>Chinese Adult Health Literacy Questionnaire (CAHLQ):</b> low vs. high	Field survey in Northwestern China (N=913)	<b>Health-related quality of life</b>	In the Hui group, low HL was a sig. predictor of prevalence pain/discomfort impairments (PR 1.8830, 95% CI 1.06-1.58) but not for the Han group. For anxiety/depression the interaction effect of HL and with ethnic was sig. ( $p<.05$ ).	F

**Education**

van der Heide 2013	Cross-sectional	<b>preprimary or primary education:</b> 5.5% <b>lower secondary education:</b> 24.5% <b>upper secondary education:</b> 30.2% <b>tertiary education:</b> 39.5%	Netherlands	Dutch <b>Health Activities Literacy Scale (HALS)</b> (191 items): very poor skills (level 1) to very strong skills (level 4)	Participants in the Adult Literacy and Life Skills Survey (ALL) 25 years and older (N=5,136)	<b>Health status</b>  (general health, physical health, mental health)	HL partially mediated the relationship between education and self-reported general health, physical health and mental health ( $p<.01$ ). HL more important among participants with lower education than among those with higher education.	G
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**Mixed**

Bennett 2009	Cross-sectional	Race/Ethnicity <b>White:</b> 85.3% <b>Black:</b> 7.3% <b>Latino/Hispanic:</b> 5.1% <b>Other:</b> 2.3%  Education < high school: 24.3% = high school: 38.5% > high school: 37.3%	USA	English & Spanish <b>NAAL health literacy scale:</b> 28 health-related literacy tasks: below basic, basic, intermediate, proficient	US adults 65 years and older - nationally representative sample ( <b>Racial:</b> N=2,668; <b>Education:</b> N=2,663)	<b>Health status</b>  <b>Preventive health behaviors</b>	HL mediated relationship between racial/ethnic (black vs. white) and self-rated health status and influenza vaccination ( $p<.001$ ). HL mediates relationship between education and self-rated health status, influenza vaccination, receipt of mammography, dental care ( $p<.001$ ).	G
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## Linking Health Literacy and Health Disparities

Howard 2006	Cross- sectional	Racial/Ethnic <b>White: 87%</b> <b>Black: 13%</b>  Education <b>high school deg.: 64%</b> <b>no deg.: 36%</b>	USA	English & Spanish S- <b>TOFHLA:</b> inadequate, marginal, adequate	Elderly individuals ( $\geq 65$ years) enrolling in Medicare managed care plans in 4 different locations <b>(Racial:</b> <b>N=2,850;</b> <b>Education:</b> <b>N=3,260)</b>	<b>Physical and mental health</b>  <b>General health status</b>  <b>Receipt of vaccinations</b>	HL reduced educational disparities for physical health (decrease of adjusted difference 0.7; 95% CI 0.4 to 0.9), mental health (decrease of adjusted difference 0.3; 95% CI 0.1-0.5), to a lesser extent for health status and very small extent for vaccination receipt. HL reduced racial disparities for physical health (decrease of adjusted difference 0.6; 95% CI 0.3 to 0.9), mental health (decrease of adjusted difference 0.3; 95% CI 0.1-0.5), to a lesser extent for self- rated health status and very small extent for vaccination receipt.	F
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**Table 1: Significant (sig.); Non-significant (n.sig.); Limited English Proficiency (LEP); African-American (AA); Categorizations of race/ethnicity reported as in the studies.**  
<sup>1</sup>Chew et al., 2008.

**Cancer Disparities**

<b>First Author</b>	<b>Design</b>	<b>Participants</b>	<b>Country</b>	<b>Instrument Cut off points</b>	<b>Sample</b>	<b>Outcomes assessed</b>	<b>Associations</b>	<b>Quality</b>
<b>Race/Ethnicity</b>								
Bennett 1998	Cross- sectional	<b>White: 49%</b> <b>Black: 51%</b>	USA	English <b>REALM</b> : 6th vs. 3rd grade	Men at prostate cancer clinics (1.) a university hospital and (2.) VA medical center (N=212)	<b>Stage of presentation with prostate cancer</b>	After adjustment for HL, and other covariates, race was not a sig. predictor anymore. However, also HL (OR 1.6; 95% CI 0.8- 3.4) was also no longer sig. associated with stage of presentation with prostate cancer	G
Freedman 2015	Cross- sectional	<b>White: 44.5%</b> <b>AA: 28.5%</b> <b>Hispanic: 27%</b>	USA	English & Spanish <b>Three Health Literacy Screeners</b> <sup>1</sup> : continuous	Female breast cancer patients: population- based cohort (N=500)	<b>Knowledge about one's breast tumor characteristics</b>	HL reduced differences in Hispanic women (vs. white women) for knowing and correctness about their breast cancer characteristics ( $p < .05$ ). HL did not reduce differences in black women (vs. white women). Overall HL did not eliminate most of the racial differences found.	F
Matsuya- ma 2011	Cross- sectional	<b>Non-hispanic white: 55.1%</b> <b>AA: 44.9%</b>	USA	English <b>REALM, S- TOFHLA</b> : continuous	Newly diagnosed adults with solid tumor cancers, stages II-IV who would be receiving treatment at a cancer center (N=138)	<b>Self-reported cancer information needs</b>	AA race was. associated with greater information need but HL was not sig. associated with information needs. Educational attainment reduced the effect of race for most variables, including HL, on information needs to n.sig..	F
Wolf 2006	Cross- sectional	<b>White: 31.5%</b> <b>AA: 68.5%</b>	USA	English <b>REALM</b> : low marginal, functional	Men with newly diagnosed prostate cancer in outpatient oncology or urology clinics in four clinics (N=308)	<b>Prostate- specific antigen (PSA) levels: medical charts</b>	After adjustment for HL skills and age, being black was n.sig. associated anymore with PSA levels. The inclusion of HL contributed to a reduction of 35% in the association between race and PSA level (without HL, AOR 4.6, 95% CI 2.0-9.5 vs. with HL, AOR 3.0, 95% CI 0.8-9.1)	G

## Linking Health Literacy and Health Disparities

Song 2014	Cross- sectional	<b>Caucasian-American:</b> <b>49.8%</b> <b>AA: 50.2%</b>	USA	English <b>REALM:</b> <high school vs. ≥high school	Participants of a prostate-cancer population based cohort study, 1 to 27 months after diagnosis ( <b>N=1854</b> )	<b>Patient- provider communication</b>  (content of dialogue, affective component. nonverbal behaviors)	N.sig. racial differences with regard to patient-provider communication. Sig. differences in HL between White and AA. HL ( $r = -0.089$ , $p = .178$ ) was not a sig. predictor in the final model, neither was race, but amongst others education ( $r = 0.19$ , $p = .01$ ).	G
<b>Mixed</b>								
Hovick 2014	Cross- sectional	Racial/Ethnic <b>White: 50%</b> <b>AA: 25%</b> <b>Hispanic: 25%</b>  Education (continuous) high school diploma: 97%  Income (continuous) below US-\$ 20000: 24%	USA	English <b>NVS:</b> continuous	National online research panel using purposive sampling strategy ( <b>N=1007</b> )	<b>Cancer risk knowledge</b>  <b>Cancer risk information seeking</b>	HL did not mediate the relationship of SES/race and cancer risk information seeking but it mediated the effects of income, education and race/ethnicity (Hispanic, Black vs. White) on cancer risk knowledge ( $p < .01$ )	F

**Table 2: Significant (sig.); Non-significant (n.sig.); Limited English Proficiency (LEP); African-American (AA); Categorizations of race/ethnicity reported as in the studies.**

<sup>1</sup> Chew et al., 2008.

### Medication Adherence/Management<sup>1</sup>

First Author	Design	Participants	Country	Instrument Cut off points	Sample	Outcomes assessed	Associations	Quality
<b>Race/Ethnicity</b>								
Bailey 2009	Cross-sectional	<b>White: 42%</b> <b>AA: 58%</b>	USA	English <b>REALM</b> : low, marginal, adequate	Adults in three outpatient family medicine clinics in (N=355)	<b>Understanding of dosage instructions for a liquid medication commonly prescribed for children</b>	Inclusion of HL reduced the effect of race on misunderstanding to n.sig.. Marginal (AOR 2.20, 95% CI 1.19-3.97) and inadequate HL (AOR 2.90, 95% CI 1.41-6.00) remained sig. predictors of misunderstanding.	F
Osborn 2007	Cross-sectional	<b>White: 54.9%</b> <b>Black: 45.1%</b>	USA	English <b>REALM</b> : low (≤6th grade), marginal (7th-8th grade), adequate (9th grade),	HIV patients on one or more antiretroviral medications at two outpatient infectious disease clinics (N=204)	<b>Self-reported HIV-medication adherence</b>	When HL was included in a regression model the effect of black race on medication adherences was reduced by 25% to non-significant (AOR 1.80, 95% CI 0.51-5.85), low HL remained a significant predictor (AOR 2.12; 95% CI 1.93-2.32)	G
Osborn 2011	Cross-sectional	<b>White: 65%</b> <b>Black: 35%</b>	USA	English <b>REALM</b> , <b>WRAT-3</b> : less than 9th grade, 9th grade or higher; <b>Diabetes Numeracy Test</b> : Quartiles	Adults with type 2 diabetes from two primary care and two diabetes specialty clinics (N=383)	<b>Self-reported diabetes medication adherence</b>	HL was associated with adherence ( $r=.12$ , $p<.02$ ), but diabetes-related numeracy and general numeracy were not associated with adherence. HL diminished the effect of race on adherence to n.sig.	G
Waldrop-Valverde 2010	Cross-sectional	<b>Non-AA: 16%</b> <b>AA: 84%</b>	USA	English & Spanish <b>TOFHLA</b> : continuous. English & Spanish applied problems subtests of the <b>Woodcock Johnson – III Tests of Achievement</b> : continuous	HIV patients at HIV care clinics who were enrolled in an AIDS Drug Assistance Program (N=207)	<b>Medication management capacity (mock)</b>	No significant differences with regard to HL found for different racial groups but for numeracy. Numeracy mediated the effect of race on poor medication management. Numeracy was significantly associated with medication management ( $r=0.67$ , $p<.001$ )	G

<b>Gender</b>								
Waldrop-Valverde 2009	Cross-sectional	<b>Men: 58%</b> <b>Women: 42%</b>	USA	English & Spanish TOFHLA: continuous. English & Spanish applied problems subtests of the <b>Woodcock Johnson – III Tests of Achievement:</b> continuous	HIV patients at HIV care clinics who were enrolled in an AIDS Drug Assistance Program and currently received/about to start antiretroviral treatment. (N=155)	<b>Medication management capacity (mock)</b>	No significant differences with regard to HL found for gender but for numeracy. Numeracy mediated the relationship between gender and medication management (a: $\beta = -0.428, p < .01$ , b: $\beta = 0.644, p < .05$ )	G

**Table 3: Significant (sig.); Non-significant (n.sig.); Limited English Proficiency (LEP); African-American (AA); Categorizations of race/ethnicity reported as in the studies.**

<sup>1</sup> Yin et al. (2009) reported on “Medication Adherence & Management” and “Other Outcomes”.

**Disease Control**

<b>First Author</b>	<b>Design</b>	<b>Participants</b>	<b>Country</b>	<b>Instrument Cut off points</b>	<b>Sample</b>	<b>Outcomes assessed</b>	<b>Associations</b>	<b>Quality</b>
<b>Race/Ethnicity</b>								
Curtis 2012	Cohort Study	<b>White/Other: 15%</b> <b>AA: 56%</b> <b>Latino: 29%</b>	USA	English <b>REALM</b> : limited vs. adequate	Asthma patients, 18-40 years old: four school sampling groups (N=348)	<b>Six follow-up interviews on asthma quality of life (AQOL), asthma-related emergency department visits, hospitalizations , asthma control</b>	HL reduced effect of race between Latinos and Whites for quality of life and asthma control ( $p<.01$ ) to n.sig.. HL reduced the effect of race on disparities between AAs and Whites for asthma control, ER visits and asthma quality of life to n.sig.. Only the risk for asthma-related hospitalization for AAs remained (RR=2.97; 95 CI=1.09, 8.12, $p=.03$ ).	G
Osborn 2009	Cross-sectional	<b>White: 65%</b> <b>Black: 35%</b>	USA	English <b>REALM</b> , <b>WRAT-3</b> : less than 9th grade, 9th grade or higher; <b>Diabetes Numeracy Test</b> : Quartiles	Adults with type 2 diabetes from two primary care and two diabetes specialty clinics (N=398)	<b>Glycemic control (Chart review: most recent A1C value)</b>	HL and general numeracy n.sig. predictors of glycemic control. Diabetes-related numeracy ( $r=-0.17$ , $p<.01$ ) diminished the effect of AA race on glycemic control to n.sig..	G
Sperber 2013	RCT	<b>White : 54%</b> <b>Black: 43%</b>	USA	<b>REALM</b> : low vs. high	Participants enrolled in primary care at a VA medical center with diagnosis of hip and/or knee osteoarthritis and persistent, current self-reported joint symptoms (N=461)	<b>Effects of a 12-months telephone-based osteoarthritis self-management support intervention: Arthritis outcomes</b>	In the telephone-based osteoarthritis (OA) self-management support intervention compared to the usual care arm ( $p<.05$ ) a sig. interaction effect for race and HL on change in pain was found; non-whites with low HL in the intervention had the highest improvement in pain. For mobility, walking and bending, affect, general pain and self-efficacy no sig. effects were found.	G

**Education**

Pandit 2009	Cross-sectional	<b>grade 1–8: 15.5%</b> <b>grade 9–11: 15.5%</b> <b>= high school: 36%</b> <b>&gt; high school: 33%</b>	USA	English <b>S-TOFHLA</b> : five categories	Patients with diagnosed hypertension and scheduled appointments at six primary care safety net clinics (N=289)	<b>Hypertension knowledge and control</b>	When HL was added to models that included only education, the association between education and knowledge was diminished to n.sig. (Grades 1-8: $\beta = -.30$ , 95% CI -1.44–0.83), whereas the association between education and hypertension control was only minimally reduced (AOR 2.46, 95% CI 2.10–2.88). Limited HL was associated with hypertension control in the final adjusted model (AOR 2.68, 95% CI 1.54–4.70). No sig. interaction effects were found.	G
Schillinger 2006	Cross-sectional	<b>&lt;high school graduate: 46.8%</b> <b>high school graduate or GED: 24.1%</b> <b>technical school or college attendance or graduation: 29.1%</b>	USA	English & Spanish <b>S-TOFHLA</b> : continuous	Type 2 diabetes patients from two primary care clinics (N=395)	<b>Glycemic control (Chart review: most recent A1C value)</b>	HL sig. mediated the effect of education on A1C ( $p < .05$ ), the direct association between education and A1c diminished to n.sig..	G

**Table 4: Significant (sig.); Non-significant (n.sig.); Limited English Proficiency (LEP); African-American (AA); Categorizations of race/ethnicity reported as in the studies.**

**Preventive Care<sup>1</sup>**

<b>First Author</b>	<b>Design</b>	<b>Participants</b>	<b>Country</b>	<b>Instrument Cut off points</b>	<b>Sample</b>	<b>Outcomes assessed</b>	<b>Associations</b>	<b>Quality</b>
Lindau 2002	Cross-sectional	<b>White: 14%</b> <b>AA: 58%</b> <b>Hispanic: 18%</b> <b>Other: 10%</b>	USA	English <b>REALM</b> : inadequate, marginal, adequate	Women in ambulatory women`s clinics at an academic medical center ( <b>N=529</b> )	<b>Cervical cancer screening history and knowledge</b>	When adjusting for HL, ethnicity was not a sig. predictor of cervical cancer screening knowledge (AOR 2.25; 95% CI, 1.05-4.80). No racial differences with regard to behavioral variables found.	F
Sentell 2013	Cross-sectional	<b>White : 91%</b> (1% LEP) <b>Asian: 9%</b> (33.5% LEP)	USA	English, Spanish, Chinese (Mandarin, Cantonese), Korean, and Vietnamese: <b>two subjective proxy measures of health literacy</b> : continuous.	Participants 50- 75 years old. 2007 California Health Interview Survey (CHIS) ( <b>N= 15,888</b> )	<b>Compliance with colorectal screening guidelines</b>	Low HL only was not a sig. predictor among Asians (OR 0.71, 95% CI 0.39-1.28) for meeting colorectal cancer screening guidelines but LEP-only was a sig. predictor (OR 0.62, 95% CI 0.38-0.99). Both LEP and low HL was sig. associated with having a lower likelihood of cancer screening (OR 0.50, 95% CI 0.28-0.89).	F

**Table 5: Significant (sig.); Non-significant (n.sig.); Limited English Proficiency (LEP); African-American (AA); Categorizations of race/ethnicity reported as in the studies.**  
<sup>1</sup> Bennett, Chen, Soroui, & White, S. (2009); Howard, Sentell, & Gazmararian (2006) reported on “Self-reported Health Status” and “Preventive Care”.

**End of Life Decisions**

<b>First Author</b>	<b>Design</b>	<b>Participants</b>	<b>Country</b>	<b>Instrument Cut off points</b>	<b>Sample</b>	<b>Outcomes assessed</b>	<b>Associations</b>	<b>Quality</b>
Sudore 2010	Cross-sectional	<b>White: 25%</b> <b>AA: 24%</b> <b>Latino: 31%</b> <b>Asian/Pacific Islander: 9%</b> <b>Multiracial: 10%</b>	USA	English & Spanish S-TOFHLA: limited vs. adequate	General medicine outpatients (≥50 years) in a county hospital (N=205)	<b>Decisional uncertainty about making advance treatment decisions</b>	Adjusted analysis: adequate HL (AOR 2.11, 95% CI 1.03-4.33), being Latino (AOR 2.50, 95% CI 1.01-6.16) or Asian-Pacific Islander (AOR 4.25, 95% CI 1.22-14.76) vs. White remained independently associated with uncertainty about treatment (Black was not associated at all). Magnitude of effect of race did not change significantly when HL was added to the model.	F
Volandes 2008	Cross-sectional experimental study	<b>White: 44%</b> <b>AA: 56%</b>	USA	English <b>REALM</b> : low, marginal, adequate	Patients (≥40 years) scheduled to see a general internist, at six primary care clinics (N=144)	<b>End-of-life care preferences</b>	Before experimental stimulus: Adjusted analysis: HL mediated the relationship between race and end-of-life preferences for African-Americans (Low HL: AOR 7.3, 95% CI 2.1-24.2; Marginal HL: AOR 5.1, 95% CI 1.6-16.3)	F
Waite 2013	Cross-sectional	<b>White: 56.9%</b> <b>(6.9% “other”)</b> <b>AA: 43.4%</b>	USA	English <b>TOFHLA</b> : inadequate, marginal, and adequate	Participants (55-74 years) at one academic general internal medicine clinic or four health centers (N=784)	<b>Having an advance directive</b>	Introduction of HL (low HL: RR 0.45, 95% CI 0.22-0.95) into multivariable model reduced influence of race but AA race remained sig. associated (RR 0.64, 95% CI 0.47-0.88) with having an advance directive.	G

**Table 6: Significant (sig.); Non-significant (n.sig.); Limited English Proficiency (LEP); African-American (AA); Categorizations of race/ethnicity reported as in the studies.**

**Other Health Outcomes**

<b>First Author</b>	<b>Design</b>	<b>Participants</b>	<b>Country</b>	<b>Instrument Cut off points</b>	<b>Sample</b>	<b>Outcomes assessed</b>	<b>Associations</b>	<b>Quality</b>
<b>Race/Ethnicity</b>								
Bains 2011	Cross-sectional	<b>White: 56%</b> <b>AA: 41%</b> <b>Hispanic/Other: 3%</b>	USA	English <b>REALM-R</b> : inadequate vs. adequate	Patients at an adult primary care clinic (N=347)	<b>Complementary and alternative medicine (CAM) usage</b>	Sig. interaction between race and HL. Whites with adequate HL were more likely to use CAM (adjusted OR 9.42, 95% CI: 1.66-53.5, <i>p</i> =.01) but in AAs adequate HL was not sig. related to CAM usage (adjusted OR 0.97, 95% CI: 0.27-3.48).	F
Langford 2012	Cross-sectional	<b>White: 81%</b> <b>Black: 10%</b> <b>Hispanic: 9%</b>	USA	English & Spanish Numeracy: <b>three subjective measurements (HINTS 2007)</b> : Likert-type scale	Health Information National Trends Survey (HINTS): nationally representative sample (N=6,754)	<b>Awareness of Direct-to-consumer (DTC) genetic tests</b>	When two numeracy variables were added to the model, the effect of black (vs. white) was no longer sig. (OR=0.84; CI 0.69-1.04). Hispanics did not sig. differ from Whites with regard to DTC genetic tests awareness. No sign. interaction of race/ethnicity with SES and numeracy variables DTC genetic tests awareness.	F
Smith 2012	Cross-sectional	<b>English-speaking: 50%</b> <b>Spanish-speaking: 50%</b>	USA	English & Spanish <b>TOFHLA</b> : low, medium, high	Patients in an ED who had received instructions for a follow-up appointment and/or medication refill within one week (N=100)	<b>Adherence to ED discharge instructions</b>	Spanish-speaking participants with low level of HL, were sig. less likely than English-speakers to show up for follow-up appointments ( <i>p</i> <.001). Spanish-speaking participants with high HL level were more likely than the other groups to have understood their discharge instructions.	P
Gardiner 2013	Cross-sectional	<b>Non-Hispanic White: 29%</b> <b>Non-Hispanic Black: 52%</b> <b>Hispanic/other race: 19%</b>	USA	English <b>REALM</b> : low vs. high	Patients in an inner-city hospital (N=581)	<b>Usage of complementary and alternative medicine (CAM)</b>	Sig. interaction found between HL and race for any CAM use and for provider-delivered therapies. Use of any CAM among White (OR 3.68, 95% CI 1.27-9.9) or Hispanic/other race (OR 3.40, 95% CI 1.46-7.91) was sig. higher among those with higher HL. Hispanics/other race with higher HL were more likely to use provider-	F

delivered therapies (OR 3.59, 95% CI 1.27-10.19).

**Mixed**

Mottus 2014	Cross-sectional	<p>Education</p> <p><b>No qualification: 17% O-level: 39%</b>  <b>A-level: 16.3%</b>  <b>(Semi)professional: 12.2%</b>  <b>University degree: 15.5%</b></p> <p>Occupational social class  <b>Unskilled: 0.5%</b>  <b>Semiskilled: 3.4%, Skilled manual: 16.6%</b>  <b>Skilled non-manual: 21.5%</b>  <b>Intermediate: 38.2%</b>  <b>Professional: 19.7%</b></p>	Scotland	British versions of: <b>REALM: , S-TOFHLA passage B, NVS:</b> all continuous combined into a latent HL factor	Lothian Birth Cohort 1936 – participants at around Age 73 years (N=730)	<p>Three objective health outcomes in older people:</p> <p><b>General physical fitness</b></p> <p><b>BMI</b></p> <p><b>Number of natural teeth</b></p>	Lower HL was linked to worse health outcomes, but educational and occupational level, as well as cognitive abilities, accounted for most of these relationships. After adjusting for covariates (including education and occupation), only physical fitness was significantly associated with HL.	G
Yin. 2009	Cross-sectional	<p><b>Child disparities</b></p> <p>Parent’s education  <b>Still in school: 0.5%</b>  <b>&lt;High school: 13.7%</b>  <b>= High school: 29.5%</b>  <b>&gt;High school: 56.3%</b></p> <p>Race/Ethnicity  <b>Non-Hispanic White: 66.1%</b>  <b>Non-Hispanic Black: 12.2%</b>  <b>Hispanic: 16.1%</b>  <b>Other: 5.7%</b></p> <p>Income  <b>&lt; Poverty threshold: 18.2%</b>  <b>100%-175% of poverty threshold 16.25%</b>  <b>&gt;175% of poverty threshold: 58%</b></p> <p>English Proficiency:  <b>Understands very well: 83.1%</b>  <b>Understands well: 10.8%</b>  <b>Understands not well/not</b></p>	USA	English & Spanish <b>NAAL health literacy scale:</b> 13 out of 28 health-related literacy tasks: Below basic, Basic, Intermediate, Proficient	Parents of children - nationally representative sample (N=6,100)	<p><b>Child Health Insurance status</b></p> <p><b>Difficulty understanding OTC-medication labels</b></p> <p><b>Food label use</b></p>	After inclusion of HL (below basic HL: OR: 2.4, 95% CI 1.1– 4.9) education and race/ethnicity was no longer a sig. predictor of health insurance status. Education, race/ethnicity and income were no longer significant after including HL (below basic HL: OR: 3.4, 95% CI 1.6–7.4) in predicting understanding of OTC medication labels. HL was n.sig. related to food-label use.	F

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at all: 6.1%

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**Table 7: Significant (sig.); Non-significant (n.sig.); Limited English Proficiency (LEP); African-American (AA); Categorizations of race/ethnicity reported as in the studies.**