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Health literacy among newly arrived refugees in Sweden

and implications for health and healthcare

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Abstract

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The overall aim of this thesis was to examine the distribution of health literacy (HL) levels in newly arrived Arabic-, Dari-, or Somali-speaking refugees in Sweden. Further aims were to investigate sociodemographic characteristics associated with inadequate HL in this group, and to investigate whether HL levels are associated with experiences of the health examination for asylum seekers (HEA), health seeking behaviour and health.

Three quantitative cross-sectional studies, using data from two different surveys, were conducted among Arabic-, Dari-, and Somali-speaking, newly arrived refugees taking part in courses in Swedish for immigrants or civic orientation. In addition, an explorative qualitative study, based on focus group discussions, was performed on Arabic- and Somali-speaking newly arrived refugees who had taken part in an HEA. All data were collected 2013-2016. The quantitative data were analysed using different statistical methods, foremost descriptive statistics and univariate and multivariate binary logistic regression analyses. The qualitative data were analysed using Graneheim and Lundman's method for latent content analysis.

The main findings were that the majority of Arabic-, Dari-, or Somali-speaking refugees in Sweden have limited functional health literacy (FHL) and/or limited comprehensive health literacy (CHL). Having a low education level and/or being born in Somalia were associated with having inadequate FHL, but not with having inadequate CHL. Limited FHL was associated with inadequate CHL. Experiences of poor quality of communication and having benefited little from the HEA were more common among those with limited CHL, as compared to those with higher CHL. Experiences of communication problems and a lack of information related to the HEA were found in the qualitative studies as well. In addition, it was more common that those with limited CHL reported poor general health and impaired psychological well-being, and that they had refrained from seeking healthcare.

In conclusion: limited HL is common among newly arrived refugees in Sweden and seems to be of importance for the experience of the HEA, health-seeking behaviour and health. HL needs to be taken into consideration in the work with refugees in order to increase equity in healthcare and health.

Keywords: Health literacy, S-FHL, HLS-EU-Q16, Asylum seeker, Migrant, Immigrant, Experiences, Health check-up, Communication, Information, Self-perceived health, Mental health, Health-seeking behaviour, Refrained from healthcare, Screening, Disease prevention, Health promotion, Quality of care, Equity in health

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To all newly arrived refugees,
*because I want you to get a good start
in the Swedish society*

To my family,
because you are always there for me

“If we want equity, we need to make health literacy a priority”
- Sylvia Mathews Burwell

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I Wångdahl, J., Lytsy, P., Mårtensson, L., Westerling, R. (2014). **Health literacy among refugees in Sweden – a cross-sectional study.** *BMC Public Health*, 14:1030
- II Wångdahl, J., Lytsy, P., Mårtensson, L., Westerling, R. (2015). **Health literacy and refugees' experiences of the health examination for asylum seekers – a Swedish cross-sectional study.** *BMC Public Health*, 15:1162
- III Wångdahl, J., Westerling, R., Lytsy, P., Mårtensson, L. **Experiences of the Health Examination for Asylum Seekers – Focus Group Discussions with Arabic and Somali Speaking Refugees in Sweden.** (Submitted).
- IV Wångdahl, J., Lytsy, P., Mårtensson, L., Westerling, R. **Poor health and refraining from seeking healthcare are associated with limited comprehensive health literacy among refugees – a Swedish cross-sectional study.** (Submitted).

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Abbreviations

CI	Confidence intervals
COR	Crude odds ratio
CHL	Comprehensive health literacy
FHL	Functional health literacy
GHQ-12	The 12-item General Health Questionnaire
HALS	The Health Activities Scale
HEA	The health examination for asylum seekers
HL	Health literacy
HLS-EU-Q16	The short version of the European health literacy questionnaire
HLS-EU-Q47	The European health literacy questionnaire
HLQ	The Health Literacy Questionnaire
ICESCR	The International Covenant on Economic, Social and Cultural Rights
IOM	The Institute of Medicine (Washington, DC, USA)
JCCHL scale	The Japanese Communicative and Critical Health Literacy scale
JFHL scale	The Japanese Functional Health Literacy scale
NAAL	The National Assessment of Adult Literacy
NVS	The Newest Vital Sign
OR	Odds ratio
REALM	The Rapid Estimate of Adult Literacy in Medicine
S-CCHL scale	The Swedish Communicative and Critical Health Literacy scale
S-FHL scale	The Swedish Functional Health Literacy scale
SFI	Swedish language schools for immigrants
SPSS	Statistical Package for the Social Sciences
TOFHLA	The Test of Functional Health Literacy in Adults
UDHR	UN's Declaration of Human Rights
UNHCR	The United Nations High Commissioner for Refugees
WHO	The World Health Organization

Prologue

The journey of this thesis started many years ago, before I really knew that it was the start of a long journey that would lead to a Doctoral degree.

I still remember when I was browsing booklets with university programmes to find something I was interested in. My choice fell on health education at the University of Gävle. However, as I preferred a degree in public health rather than in education, the last six months of the health education programme in Gävle was exchanged for six months at Örebro University, at the public health programme there. Along with studies in Örebro, I travelled across to various supermarkets within a 100-km radius every other evening to host workshops including theoretical lectures in health and nutrition, and practical cooking courses for their staff.

After graduating, I tested my entrepreneurship by running my own company, in which I mainly offered messages and taught nutrition and health, before getting my first “real” work. This was as a coordinator and health communicator in “Hälsoteket i Angered”, a health promoting activity centre in a municipality with a large proportion of migrants, outside Gothenburg. This was a real challenge, both because I was half as old as most of the colleagues I was leading, and because the previous coordinator quit before I started. However, it was a great opportunity for putting knowledge into practice. I am very grateful for the freedom I had to form and develop Hälsoteket, together with my colleagues, into what we believed that the citizens in the area needed and wanted. It also gave me the chance to, among many other things, practice everything from administration to standing in front of groups lecturing, and leading classes in mindfulness and physical activities. In addition, I met a variety of people who came from all over the world, many of whom trusted me and shared with me their life stories. Seeing that many of those who participated in our activities improved their health and became less isolated was fantastic.

However, being about and sharing information about Hälsoteket with others that wanted to have the same kind of centre in their community, I felt that our experiences of our work and its leading to better health were not sufficient. Politicians and funding agencies wanted hard facts, quantitative data that supported our qualitative experiences.

Falling in love with a man from another city suddenly gave me an opportunity to follow my plan to continue my academic career to a Master degree in public health. The focus of my thesis was given: I should examine how Hälsoeteket affected the participants' health.

Moving to Stockholm and starting the Master programme in Health Promotion and Health Economics at Karolinska Institutet it became clear that it would not be easy. First, I had to determine what I should measure, and, second, I had to determine how should I measure it. It was then that I must have heard or read about health literacy for the first time. It completely hit the spot: that was *the concept* for me. Even if I did not know about it before, it described so well what we worked with and strived to increase in the work at Hälsoeteket. It was perfect, then, that I could start, create a questionnaire with questions of interest and start collecting data.

But it was not that easy. No health literacy assessment was translated into Swedish. Because of this my master's thesis instead became to develop the first existing health literacy instrument in Swedish (the S C& CHL). During that process, I came into contact with Lena Mårtensson, now one of my co-supervisors. I e-mailed her to ask if she would be able to be among the members of the expert committee that would give feedback on the instrument. She did, but also asked *me* if it would be ok for me if she became my co-supervisor for the Master thesis as well. What was I to say? I was very grateful—even more so when my first supervisor left the country, and could not continue to supervise me before I finished the master's thesis.

While I was finishing my master's thesis I found an opportunity to work in a project at Uppsala University with educating future study circle leaders in health. These were people who themselves had previously migrated to Sweden. After this training period, they were to run their own study circles in health, in their native language, for other migrants that had arrived more recently. Again, I got the opportunity to use my practical skills and use experience-based didactics, which I really enjoy. Still, as I was in love with the man in Stockholm, I did not want to move back to Gothenburg, even if it meant that I had to quit my secure employment at Hälsoeteket. Instead, I contacted Ragnar Westerling, who later became my supervisor for this thesis, to ask whether he had work for me. I also wrote a proposal for a PhD project, in which he showed interest.

This led to an employment at Uppsala University. The first year I mainly worked with developing a web-based course in public health, which since then has run every year. In addition to this, I translated and validated another HL instrument into Swedish (the S-FHL). I also wrote different project applications, some of them in cooperation with external partners, as it turned out that

others had plans similar to those I described in the PhD proposal. This resulted in funding for two different projects. One had the overall aim to improve the work with the health examination for asylum seekers in Sweden (Project: “Improved structure and coordination of health examinations for asylum seekers”), and the other was a project that aimed to bring long-term unemployed migrant women closer to the labour market (Project: “Athena”). Thanks to this, I became registered as a PhD student on the 28th of January 2014.

However, doing research in communities, in the “real” world, is not without its obstacles. Projects do not always proceed as planned, participants may come and go, and participation in research-related activities is voluntary. Therefore, the data from the Athena project were not optimal for use in this thesis. Still, the project gave me a great deal of experience and training in setting up a research project and analysing statistical data. The other project, however, gave me the opportunity to translate one more HL instrument into Swedish (HLS EU-Q16), translate this and S-FHL into different languages, examine HL among refugees, and identify the extent to which refugees’ HL is important for their experiences of the health examination for asylum seekers. Then, I was contacted and asked to evaluate the civic orientation in Stockholm. This provided an opportunity, once again, to collect extensive information regarding health literacy and other health-related information among newly arrived refugees. With this, data for my last article in this thesis were secured as well.

However, my main goal has never been to seek an academic career for the reason of getting a fancy title. What is most important for me is that what I do can make a difference and lead to better health for others, especially for those with poorer health than the general population, and unnecessarily poor health because of structural barriers and because their needs are not met. Therefore, I say to you who read this: what you do can make a difference. If we all consider health literacy just a little when we talk about and work with health, the negative consequences of limited health literacy could be reduced. So please do!

“People cannot achieve their fullest health potential unless they are able to take control of those things which determine their health”

- Ottawa Charter for Health Promotion

Background

Introduction

In the society of today, health information targeting the indigenous population as well as refugees is produced by and may be received from many different sources, e.g., from media, internet, schools, commercials and healthcare providers [1]. It can be difficult to judge whether the information is correct and can be trusted. Individuals may also find the information difficult to understand because of limited language skills or a low quality of translations and interpreters [2-5]. Information about healthcare has become technical, advanced and very complex [6] because of the diversity of the healthcare sector and the many different professionals involved. Also, the number of conditions that can be prevented and treated has increased tremendously in the last century.

Moreover, the view of what health is, and what should be done to improve or maintain it, differs worldwide [2, 7]. In Western countries, the use of health promotion and prevention is much more established [7-10]. Furthermore, the healthcare system has become more individualized and patients are expected to take more responsibility for self-care and be more active in managing their health [6]. This makes it challenging for people to know what can be treated, as well as when and where to seek healthcare. To benefit from health information and today's care, it is therefore important to be able to find, understand, appraise and apply health information, i.e., to have sufficient comprehensive health literacy (CHL).

Refugees and health

The studies underlying this thesis focus entirely on a specific group of people: refugees. This section provides a background including how refugees are defined, how many they are, where they come from and where they go. In addition, the general health of refugees, as well as the health examination for asylum seekers (HEA), are described, as these are specific focus areas of the thesis.

Definition and distribution of refugees

The world today is full of war and conflict. People move between countries and arrive in countries with systems, languages and cultures more or less similar to their countries of birth. One particular group of migrants is refugees, defined as “*persons who have fled from and/or cannot return to their country for a well-founded fear of persecution, including wars or civil conflict*” [11]. According to the United Nations High Commissioner for Refugees (UNHCR) [12], 11.7 million people were considered to be in a refugee-like situation and 1.2 million people to be asylum-seekers worldwide at the end of 2013, when this research project started. Since then, the number of displaced persons has increased. One estimate says that the total number of asylum seekers and refugees had increased to 24.5 million in 2015 [13]. More than half (54 %) of them came from only three countries: Afghanistan, the Syrian Arab Republic, and Somalia.

Most refugees are displaced in countries bordering on their country of origin, but a large share seek asylum and settle in countries further away. One European country with a high influx of asylum-seekers and refugees is Sweden. With 156,400 new applications for asylum in 2015, more than twice as many as the year before, Sweden was the third largest recipient country in the world of new individual applications [13]. In total, about 107 000 asylum-seekers received a residence permit in Sweden in the period 2010-2015 [14].

Refugees' health

The health status and the need of help for health problems vary among refugees [5, 15-17] since they are a heterogeneous group consisting of individuals with different backgrounds and experiences. However, ill health exists, and some health problems are more common among migrants in general and refugees specifically [17, 18]. Two common health problems are psychological ill health [19-24] and low perceived self-rated health [20, 25]. The latter is serious as it predicts the risk of sick leave [26], disease, and premature death [27]. Problems with non-communicable diseases are more common [18, 28] and the prevalence of infectious disease is also higher in certain sub-groups [29]. Often refugees' health deteriorates over time [17, 30], and their poor health is sometimes identified first when they start working or participating in training for work [31]. At the same time, many refugees refrain from seeking healthcare [2, 7, 8, 32], participate in health promoting activities to a lower extent [2, 7, 8], and have unmet healthcare needs [33-35].

Many health problems are related to social determinants of health and socioeconomic factors [5, 8, 17, 36]. Refugees also experience several different

challenges that affect health during the migration process [8, 17] in their country of origin, on the way to a new country and when resettling in the new country. One challenge is to find and understand information about health and healthcare, and about how to get in contact with the healthcare and get help for health problems of concern [2, 5, 7, 8]. Communication problems between refugees and healthcare professionals are also common [3-5, 37, 38], and health information and health-promoting educational programmes often reach migrants to a lesser extent than people in general [7, 39].

The health examination for asylum seekers

Many refugees' first contact with healthcare and health information in the new country are when they participate in an HEA [10]. The overall purpose of the HEA in most countries is to identify poor health in order to secure the well-being of asylum seekers, and to guarantee the safety of the population in the host country [40]. Another important purpose in many countries is to give information about the health system in the country in order to increase asylum seekers' access to healthcare [41-43]. However, the content of an HEA and whether it is mandatory or voluntary varies between countries [40].

In Sweden, all asylum seekers should, unless this is found to be clearly unnecessary, be offered an HEA free of charge either before or after having received a residence permit as a seeker of asylum [43]. It is voluntarily [43] and should be based on informed consent [44]. The HEA should include a conversation about the participant's past and present physical and mental health [43]. Questions of importance from the point of view of infectious control should also be raised. Physical examination and further medical investigations or sampling may be carried out. Furthermore, the participant should be informed about his or her rights and access to required health- and dental care.

The proportion of asylum seekers who participate in an HEA differs across the country and has declined in recent years. According to national statistics, only about 40% attended an HEA in 2014 [45], which must be taken seriously, as low participation in the HEA constitutes a threat to society: it may contribute to inequality in health status [46] and pose a threat for individuals since it may increase the risk for spreading infectious diseases [47]. According to people working with the HEA in healthcare and at the Swedish Board of Migration [38, 48, 49], the relatively low proportion depends both on structural factors—such as inadequate systems for transferring information and poor quality of information about the HEA, and individual factors, such as asylum seekers' previous experience of healthcare and authorities, and their limited health literacy (HL). Knowledge of refugees' experiences regarding communication and health information during the HEA and its usefulness was very limited when this research project started.

Health literacy

This section describes what HL is, the development of the concept and how it is related to health.

Definitions of and the history of health literacy

Health literacy is regarded as a social determinant for health [50]. Limited HL hampers active choices and people's possibilities of acting responsibly to obtain and maintain good health [50]. Moreover, HL can be a useful indicator when evaluating health-promoting interventions, as HL may affect people's health behaviours, which in turn may affect people's health status. [51, 52].

The term HL was used in a scientific paper for the first time in the 1970s [53], but it was not until the early 1990s that it started to appear in the literature more frequently. Since then, the number of papers focusing on HL has increased almost exponentially [54]. In various papers, HL has been defined in 20 different ways, and there is still no consensus about the definition of, or conceptual framework for, HL [55]. However, existing definitions of HL can roughly be divided into two groups: those using a *new public health* perspective and those using a *medical* perspective [55-57].

The inclusive *comprehensive HL* (CHL) concept defined by Sorensen et al. is based on their integrated model of HL [55]:

“[Comprehensive]HL is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgments and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course”[55].

This definition encompasses the public health perspective, captures 17 other definitions of HL, and is the one in focus in this thesis.

One way of subdividing comprehensive HL distinguishes between functional, communicative and critical HL. *Functional HL* (FHL) focuses on an individual's ability to read information and instructions about health and the capacity to apply these skills in everyday situations [56]. *Communicative HL* focuses on more advanced cognitive and literacy skills which, together with social skills, can be used to extract information, to communicate with others and to apply the new information to changing environments [56]. *Critical HL* focuses on the same skills as functional and communicative HL plus critical skills needed to analyse information to exert greater control over life events and situations [56].

Comprehensive HL goes beyond specific abilities, including also competencies needed to meet demands on health in modern society. It is seen as an asset for health [55] and a continuous property that varies dynamically and is closely related to the context [57]. Furthermore, CHL is not considered to be isolated to the individual; rather, it is something that develops in relation to the environment [58, 59]. This means, for example, that a person could have adequate CHL in one country and inadequate CHL in another. A person could also have inadequate FHL while simultaneously having adequate communicative and critical HL or vice versa [60, 61]. For example, an illiterate person could be very good at communicating with others about health, or a literate person could have difficulties orienting themselves in the healthcare system.

Health literacy from the medical perspective focuses mainly on individuals' abilities to read and understand letters, numbers and words often used in information and instructions in the medical context [56, 57]. It is a measure of specific knowledge and skills such as listening, speaking, arithmetical writing, writing and reading, and of health-related print literacy and health-related oral literacy [55]. Health literacy from the medical perspective overlaps to a large extent with the *functional HL* concept used in the public health perspective. But there are differences. From the medical perspective, HL is seen mainly as a risk for poor health and something you either have or do not have, i.e., it is a polarized phenomenon [57], instead of a continuous, dynamic asset for health [55, 57]. Moreover, it does not include communicative or critical skills.

Most HL research has focused on FHL from the medical perspective and has been carried out in the US, Australia, and Canada [55, 62, 63]. In Europe, the awareness of and research on HL has exploded in the last decade and the focus is now more on CHL. However, in the scientific literature, it is not always clearly stated which definition of HL or what perspective of HL is used. This makes the research area rather complex and diffuse. In this thesis I have chosen to write out FHL or CHL, instead of only HL, when possible. When using only HL, I refer to HL as a whole and do not distinguish between functional and comprehensive HL.

Consequences of limited health literacy

Research shows that people with limited FHL often have difficulties interpreting labels and health messages [64], are ashamed of their limited FHL [65, 66] and ask fewer questions in medical encounters [67]. FHL has also been shown to be associated with poorer knowledge about and participation in disease prevention [64, 68, 69], greater use of healthcare [70, 71], poorer adherence to medicine and treatment instruction [64, 72, 73], and less satisfaction with care received in general practice [74] and with the communication with healthcare providers [75]. There are mixed results regarding access to healthcare,

knowledge of health issues, and risk behaviour; some studies show associations with FHL, others do not [72]. This might be explained by the use of different HL measurements, and by study populations with different characteristics.

Limited FHL and limited CHL have been shown to be associated with less optimal communication in healthcare encounters [67, 70], greater use of emergency care [64, 76-78] and more hospitalization [64, 77, 78]. Regarding health status, limited FHL has been shown to associate with poor mental health [79, 80] and with increased risks of morbidity and premature death [64]. Associations have also been shown between both limited FHL and limited CHL and poor self-perceived general health [72, 77, 78, 81]. Limited CHL has been shown to be associated with long-term illness [77, 78], but mixed results exist regarding its association with physical activity. In one study, an association was found between limited CHL and low physical activity [78], but this was not found in another study [81].

Distribution of limited health literacy

Limited HL is more common in some population sub-groups than in others. Many studies show that high age [64, 77, 82, 83], low education [78, 83-85] and poor socio-economic status [77, 82, 85, 86] are strong predictors for limited FHL and/or CHL. However, other studies find no significant associations between CHL, age and education [81, 87]. Results regarding whether gender is a predictor for FHL and CHL vary as well [64, 81, 82, 84]. In addition, poor literacy [88], being an immigrant or having another ethnicity than the general population [83, 85] have been identified as predictors for limited FHL. Limited FHL as such [84] and low social status [77, 82] have been shown to predict limited CHL.

Estimations of and comparisons of the percentage of the population that has limited HL in different countries are difficult due to the many different definitions and measurements in use [64, 72, 89, 90]. However, if we are pragmatic about what definitions and measures are used, the proportion of people with limited HL appears to be considerable in many countries. Through processed health-related data from national adult literacy skills surveys, conducted in the period 2006-2012, it is known for example that 46 % in the US [91], 55 % in Canada, and 57% in Australia [90], had limited HL. In the American study, HL was defined as *“Using printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential”* [91]. In the Canadian and the Australian surveys, HL was defined as *“the knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and*

treatment, safety and accident prevention, first aid, emergencies, and staying healthy” [90].

In Europe, a large study with data from eight European countries (Austria, Bulgaria, Germany, Greece, Ireland, The Netherlands, Poland and Spain), was conducted in 2012, in which FHL and CHL were measured [78]. The definition of FHL was not described specifically but was measured through the Newest Vital Sign (NVS), which focuses on reading comprehension and numeracy skills [92]. The definition of CHL was the one developed by Sorensen et al. [82], i.e., the same as used in this thesis. The results from that survey showed that, on average, 45 % had limited FHL and 47% had limited CHL in the countries studied [78]. It is worth noting that the percentage of people with limited HL varied within sub-groups and between the countries, that migrants were excluded, and that no Nordic country was included.

Health literacy, migrants, and refugees

Globally, knowledge about the proportion of migrants and refugees that have limited FHL and CHL, as well as about the HL levels in their countries of origin, is very limited. In addition, knowledge about associations between HL, health behaviours, and health outcome in those groups and populations are lacking. At the start of this thesis project in 2014, only a few studies had been published in this domain. According to those, the proportion of migrants or refugees with limited HL in the different study populations in the US and Canada ranged between 74 and 76 %, which must be considered high [85, 93]. Except confirming previously found predictors (sex and education level) for limited FHL in general populations, one of the studies also showed that the refugees with limited FHL were more likely to be less acculturated and had poorer oral health [93].

Some qualitative studies were published, showing that limited HL among refugees could contribute to disparities [94]. Some explanations for this were that limited HL hindered the refugees from understanding health information linguistically as well as culturally, and that the healthcare does not always meet those with limited HL in an optimal way. This, in turn, led to misunderstandings and negative future health outcomes. Some articles also discussed the importance of sufficient HL and the consequences of limited HL for refugees and migrants [37, 95]. However, those were more based on theoretical and logical reasoning than on findings from studies measuring HL among refugees. The only study of which I am aware that examines levels of and associations with HL among refugees specifically—apart from those included in my thesis—is from Norway. That study shows that about 72 % of the Somali immigrant women in Oslo have limited CHL, and that this was associated with being unemployed and being less socially integrated [87].

Other concepts relating to refugees' health

This section describes some other concepts and principles that are related to refugees' health and/or healthcare. They are also related to HL, as they all stress the importance of individuals' access to health and healthcare in different ways.

The right to health

Limited HL may interfere with refugees' right to the enjoyment of "the highest attainable standard of physical and mental health", which the International Covenant on Economic, Social and Cultural Rights (ICESCR) [96] lists as a fundamental human right, to be enjoyed by every human being with no distinction of race, religion, political belief, economic or social condition [97, 98]. The right to health is also mentioned in the UN's Universal Declaration of Human Rights (UDHR) [99], and many other international treaties on human rights. These treaties contain various detailed descriptions of the right to health from different perspectives.

To clarify and operationalize what the right to health means in practice, the UN Committee on Economic, Social and Cultural Rights adopted a General Comment on the right to health [97]. According to this,

"[the right to health extends] not only to timely and appropriate healthcare but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, and adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions and access to health-related education and information, including on sexual and reproductive health" [97].

In addition, the General Comment states that the human right consists of four elements: Availability, Accessibility, Acceptability and Quality (*AAAQ*).

- *Availability* means that functioning public health and healthcare facilities, goods and services must be available in sufficient quantity within a state.
- *Accessibility* means that health facilities, goods and services must be accessible for all, and not be restricted due to physical and economic reasons or discrimination. In addition, it includes that everyone has the right to seek and receive health-related information in an accessible format.
- *Acceptability* means that health facilities, goods and services must respect medical ethics, be gender-sensitive and culturally appropriate.
- *Quality* means that health facilities, goods and services must be scientifically and medically appropriate and of good quality.

However, considering known social determinants of health [100], other human rights such as having a decent standard of living and education as well as freedom from discrimination and freedom to participate fully in the society are also important for individuals' health [100, 101]. Not considering that individuals have different HL levels and not meeting the needs of those with lowest HL could challenge their right to health, as well as other human rights. Limited HL could, for example, make it difficult to make well-founded decisions regarding one's own health, as well as the health of others [57], and actively be involved in overcoming personal, structural, social and economic barriers to health [55].

Equity in health

Equity is an ethical concept, closely related to the principle of human rights [101]. It is often included in policies and regulations in the health domain. In Sweden, the goal of the National Public Health Policy is, for example, to create social conditions that will ensure good health, on equal terms, for the entire population [102]. In addition, the Swedish Health and Medical Service Act aims to give good health and care on equal terms for the entire population [44].

According to Whitehead's definition, which is the most concise and widely used definition [103]

“Equity in health implies that ideally everyone should have fair opportunity to attain their full health potential and, more pragmatically, that no one should be disadvantaged from achieving this potential, if it can be avoided”[104].

An example of a more detailed and technical definition, developed with an aim to measure and operationalize equity, is the one by Braveman and Guskin [103]. According to them:

“Equity in health is the absence of systematic disparities in health (or in the major social determinants of health) between groups with different levels of underlying social advantage/disadvantage – that is, wealth, power or prestige. Inequities in health systematically put groups of people who are already socially disadvantaged (for example by virtue of being poor, female, and/or members of a disenfranchised racial, ethnic or religious group) at further disadvantage with respect to their health: health is essential to wellbeing and to overcoming other effects of social disadvantage. Assessing health equity requires comparing health and its social determinants between more and less advantaged groups” [101].

On the other hand, the often used antonym inequity refers, according to Whitehead, to differences that are unnecessary and avoidable, while at the same time being unfair and unjust [104]. Avoidable ill health can in short be described as health problems that cannot be accounted for on biological grounds, but are

caused by factors that can be influenced, such as poor sociodemographic and environmental conditions, or bad living, working or social conditions [46], i.e., the social determinants of health [100].

Here it must be stressed that *equity* and *equality*, which are everyday synonyms, are not the same thing in this specific context [101]. One important difference is that equity is value based, while equality is not necessarily value based. Equity also focuses on the distribution of resources and processes that drive a specific inequality, on systematic inequalities between social groups that are more or less disadvantaged, i.e., on health inequalities that are unjust or unfair. Equality, on the other hand, means that all are treated in the same way and are provided the same resources without regard to individual needs and conditions [105].

Equity in healthcare is closely related to equity in health but focuses specifically on equity in relation to the healthcare system. Whitehead defines equity in healthcare as “*equal access to available care for equal need, equal utilization for equal need, and equal quality of care for all*” [104]. Another definition is the one by Culyer and Wagstaff, stating that equity in healthcare means “*equal utilization, distribution according to need, equal access, equal health outcomes*” [106]. Other frequently used concepts in the context of equity in healthcare are *horizontal* and *vertical equity* [103, 105-107]. *Horizontal equity* may be described as equal treatment for equal need, in contrast to *vertical equity*, which would require different treatments for different needs [103, 105].

Horizontal equity means, for example, that those with equal need should have equal opportunities for accessing healthcare [107]. However, this does not necessarily mean that everyone will make equal use of those opportunities, which could be explained by various acceptable reasons. People with equal needs might, for example, due to different preferences, choose to accept or decline treatments they are offered. But there are also unacceptable reasons for missing an opportunity for care, for example, because of lack of information. If that is the case, the principle of equal care for equal needs is not fulfilled.

Vertical equity refers, for example, to people in greater need of healthcare being given priority over those with lesser needs [106] and that specific efforts must be made to deliver disease prevention for particularly vulnerable groups [105]. In other words, equity in healthcare does not mean that all people should necessarily be treated equally, but that all should be treated equivalently according to their specific conditions [46].

In Sweden, equity is stressed in the Swedish Health and Medical Act stating that the reception, care and treatment in healthcare should be equal and offered

to all regardless of, for example, personal characteristics, education, age, disability, ethnical belonging or social status [46]. In addition, it is stressed that the patients' different characteristics and prerequisites should not affect care (unless there are different medical conditions or medical needs), and that it is the healthcare's responsibility to compensate for inadequate abilities in patients. However, results from an extensive analysis of unjustified differences in care, treatment and how patients are received in the Swedish healthcare show that there exists inequity in Swedish healthcare [46]. One of the suggested explanatory factors for this is that patients' HL levels are not taken into account. That HL can have an impact on equity is also stated by Sorensen et al. who, in their integrated model of HL, assume that HL can affect equity in health, as well as that equity in health can affect HL [55].

Quality in healthcare

There are many different definitions of quality in healthcare, and no consensus as to which one is the best [108, 109]. According to Donabedian, one of the earliest and most prominent researcher in the field of quality in healthcare, quality of healthcare could be defined as "*the application of medical science and technology in a manner that maximizes its benefit to health without correspondingly increasing the risk*" [110]. According to his conceptual model for quality of healthcare, three components are important for the assessment of the quality of care: the *structure*, the *process* and the *outcome* of the care [111].

- The *structure* refers to the attributes of the settings in which the care takes place. The attributes consist of *material resources* such as facilities, equipment and money; *human resources* such as the number of and qualifications of the staff; and *organizational structure* such as the organization of the medical staff, and methods for peer review and reimbursement.
- The *process* refers to what is actually done in giving and receiving care, both by the patients themselves in order to access healthcare and use it, and by the practitioners in order to make a diagnosis and recommend or implement a treatment.
- The *outcome* refers to the effects of the care provided on the health status of the patients and the population, in which improvement of the patient's knowledge and behaviour as well as the patient's satisfaction with the care are included.

Another commonly and widely used definition is the one by the Institute of Medicine (IOM) describing the quality of the healthcare as the "*degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge*" [112]. IOM as well as the World Health Organization (WHO)

have proposed six very similar components that they use to define the quality of healthcare [113, 114], components which also could make it more clear what to focus on when assessing and promoting the quality in the healthcare. According to them, high quality healthcare should be:

- *Safe* – striving to provide care that is not harmful for the patients.
- *Effective* – providing care that is based on scientific knowledge/evidence that results in improved health outcomes for those in need.
- *Patient centred* – providing care that takes into account individual service users' preferences, needs and values and the culture of their communities.
- *Accessible/timely* – providing care that is timely, prevents long-waiting times that could be harmful both for the user and the provider, and delivers care that is geographically reasonable and that is given in a setting where skills and resources are appropriate to the medical need.
- *Efficient* – providing care in a manner that maximizes the use of resources (material as well as human resources) and avoids waste of these resources.
- *Equitable* – providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographical location or socio-economic status.

Others have also stressed that access and efficiency are important components of the quality of the healthcare [108, 111]. Campbell et al. even include access and effectiveness in their definition, by describing quality of care as “*whether individuals can access the health structures and processes of care which they need and whether the care received is effective*” [108]. In their definition, *access* refers both to *geographical/physical access* and the *availability* of health services. The former can, e.g., be limited by geographical distance to the nearest clinic, or by obstacles making it difficult for the elderly or disabled to physically access the premises. Availability refers both to the existence of health facilities and the availability of general practitioners and various specialists, and to the organizational obstacles that may limit patients' access to these resources. For example, the possibility of choosing a specific practitioner, for cultural reasons, or being referred to a specialist, are availability factors which contribute to a higher quality care. Conversely, an organization that effectively limits patients' access to specialist care if they do not speak a given language or have problems reading information must be considered to be of lower quality.

Regarding *effective*, Campbell et al. stress that healthcare must deliver intended outcomes or support desired processes. According to them, two concepts are key components for an effective healthcare: *clinical care* and *interpersonal care*. The effectiveness of clinical care refers to the extent to which it is knowledge-based, i.e., the extent to which evidence-based care—or other

care that is widely accepted and legitimized—is used. How effective inter-personal care is depends on, for example, the extent to which the healthcare is person-centred, and whether the treatment and service are consistent with patients' reasonable expectations. Similar principles are also stressed by Donabedian and many others having developed different frameworks for quality of care [109, 111].

From the patients' perspective, key domains in the quality of care are: patient-centred care, access, information and communication, courtesy and emotional support, efficiency in care/effective organization, technical quality, and structure and facilities [115, 116]. Examples of factors important for quality in the access domain according to patients are: having access to specialist care and healthcare in general within a reasonable timeframe, having access to qualified interpreters, and receiving help from providers to navigate in the healthcare system [115]. Examples of factors important in the domain of information and communication are providers with good interpersonal communication skills, quick responses to test results, complete and accurate translations, and education facilitating self-care and health promotion. Examples of factors important for the domains patient-centred care, and courtesy and emotional support, are staff that treat patients as people, that show compassion and interest in the patient's own needs, and who are willing to help with those [115, 116].

Patients' own perspectives of the quality of care are important, as those experiences can affect further health care behaviour and health outcomes [115]. In addition, many of the key domains presented above are also important for patients' satisfaction with the healthcare [117, 118], as this is an important indicator for the quality of the healthcare as well [118, 119]. Regarding HL specifically, research shows that HL is associated with both experiences of the quality of communication [120] and satisfaction in the healthcare [74].

Theoretical framework

The integrated model of health literacy

In this thesis, the integrated model of HL by Sorensen et al. [55] is used as a theoretical framework. The original article contains an extensive review of preexisting theories and concepts, condensing them into the integrated model and a new comprehensive definition of HL. Note that, while the authors themselves write simply *health literacy* for the new definition as well, this thesis uses *comprehensive health literacy* (CHL) to distinguish Sorensen et al.'s definition from other existing concepts and definitions.

The integrated model of HL combines a conceptual model including different dimensions of HL with a logical model representing the impact of societal, personal and situational factors on HL, and connects HL to health outcomes.

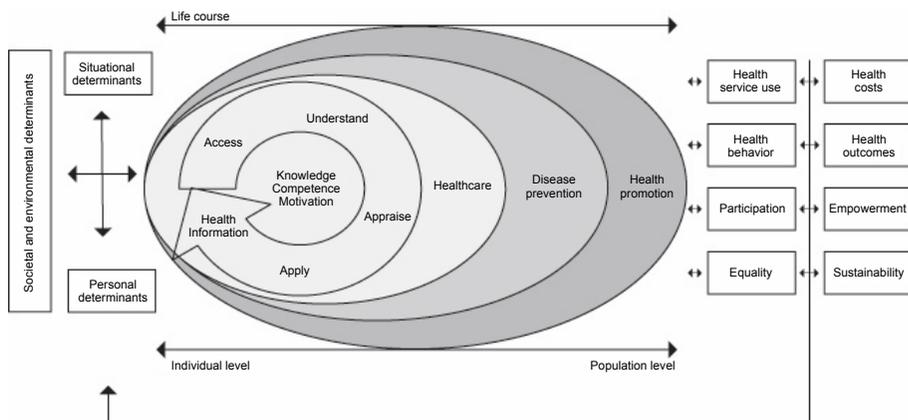


Figure 1. The integrated model of HL by Sorensen et al.

Figure adapted from the article: Sorensen K, Broucke SV, Fullam J, Doyle G, Pelikan J, Slonska Z, Brand H, HLS-EU Consortium: Health literacy and public health: A systematic review and integration of definitions and models. BMC Public Health 2012, 12(1):80. Reproduced with permission from the authors.

The centre of the model represents the core of HL: *“the knowledge, motivation and competencies of accessing, understanding, appraising and applying information to form judgment and make decisions concerning healthcare, disease prevention and health promotion”* [55].

The circular arrow illustrates the stepwise, iterative, process whereby people apply their HL skills—in addition to general literacy and numerical skills—to acquire, understand, process and apply information. Working through the steps enables people to take control over their health, and act to overcome personal, structural, social and economic barriers to health. Each step in the process requires its own type of competencies, including its own specific set of cognitive qualities. The realization of each step is also related to specific aspects of the quality of the health information provided.

In general:

- *Access* requires the ability to seek, to find and to obtain health information, and depends on, e.g., the timing and trustworthiness of information.
- *Understanding* requires the ability to comprehend accessed health information and depends on, e.g., its perceived utility and how well it is adapted to the individual.
- *Appraising* requires the ability to interpret, to filter and to critically evaluate health information and depends on, e.g., its complexity and jargon.
- *Applying* requires the ability to communicate and to use information to maintain and improve health and depends on comprehension.

The three qualities of functional, communicative and critical HL as proposed by Nutbeam [56] are incorporated in these four dimensions.

The competencies involved in the HL process enable people to navigate in the three health domains: health promotion, disease prevention and healthcare, whether as a “healthy person” in society or as a patient in healthcare. In each domain, working through each process step requires its own set of specific abilities, making it possible to identify 12 distinct dimensions of HL. Regarding health promotion, the model refers to health promotion efforts in the community, as well as the work place, the educational system, the political arena and the marketplace.

The “individual – population level” continuum illustrates the interplay between the individual and population levels (including the three health domains) and stresses that those are integrated with each other, and that individuals as well as communities, organizations and societies can be health literate. The “life course” arrow is a reminder that HL competencies develop over a lifetime and are linked to lifelong learning. They are affected by changes in experiences and knowledge, by changes in cognitive and psychosocial factors, as well as by changing contextual demands. In the context of migration, this

means that the improvement of HL in groups with inadequate HL may be part of a successful integration.

The boxes on the left present factors expected to have an impact on HL, and correspond to the different layers of determinants of health presented in Dahlgren's and Whitehead's widely used rainbow model [121]. Examples of societal and environmental factors are culture, language and societal system [55]. Situational determinants include for example social support, family and peer influences, and physical environment. Examples of personal determinants are age, gender, socio-economic status, education and literacy.

The boxes on the right list outcomes that HL has a potential to impact, and indicate relationships they have with each other. Health literacy can affect health behaviour and the use of healthcare, which in turn can affect health costs and health outcomes. Furthermore, HL can directly or indirectly influence participation and empowerment, and affect equity and sustainability of change in public health.

To summarize, the integrated HL model is very complex, and is based on a holistic view of health. It shows that HL in a wide sense—referred to as CHL in this thesis—consists of a broad range of abilities that can be influenced by various social determinants of health, and that HL is an asset for and of importance to individuals' health in their everyday life, not only in healthcare.

In this thesis, the integrated HL model is used as a theoretical framework for HL. This means that, in my view, HL is a complex phenomenon, which depends on both the individual and the society. The model is used and integrated in the studies in the thesis in different ways. In addition, the definition by Sorensen et al. [55] is used as the major definition of CHL in all studies.

The different studies examine different parts of the model, e.g., possible antecedents for HL and potential consequences of HL. Study I investigates functional and comprehensive HL among newly arrived refugees, and also looks at factors that may have an impact on refugees' HL. Studies II and III examine the relationship between HL competencies and experiences of disease prevention (HEA), while study IV measures associations between HL, health service use, and health outcomes.

In addition, the instruments in the questionnaires used in Studies I, II and IV, as well as the themes chosen for the dialogue guide in Study III, are based on the core components of the integrated HL model. However, owing to the complexity of HL, not all parts of the model are examined or discussed in the thesis.

Measuring health literacy

Measurements of individual HL can be divided into three types: population-based proxy measures, direct testing of individual health literacy skills, and self-reporting of HL [89]. Population-based proxy measures of HL are not frequently used. They have primarily been used in the US, focusing on individual functional HL or plain literacy. Two examples are the National Assessment of Adult Literacy (NAAL)[122] and the Health Activities Scale (HALS)[91].

Direct tests focus on individual functional HL [123] and have long been the most frequently used HL instruments. They typically assess people's ability to read and comprehend written words and numbers in a healthcare context. Three examples are the Test of Functional HL in Adults (TOFHLA)[124], the Rapid Estimate of Adult Literacy in Medicine (REALM) [125] and the Newest Vital Sign (NVS) [126]. A strength of these instruments is that they are rather objective, as they assess individuals' real skills and are not based on self-reporting. On the other hand, they require face-to-face interviews, and are time-consuming and medical-oriented, making them less useful for screening and in public health contexts.

The use of self-reporting measurements of HL has increased significantly in the last decade. Some instruments target functional HL but most try to measure more dimensions of HL. Ishikawa's Japanese Functional HL Scale (the JFHL scale)[127], for example, focuses on individual functional HL from a public health approach, including abilities needed both for disease prevention and health promotion [51]. The European HL questionnaire (HLS EU – Q16/47) [128, 129], the HL questionnaire (HLQ) [130] and Ishikawa's Japanese Communicative and Critical HL scale (The JCCHL scale) [131] are examples of measurement instruments aiming to assess several dimensions of an individual's HL, in healthcare as well as in other parts of society. Using self-assessments, they are easier to include in surveys. On the other hand, they are more subjective, and people may estimate their skills very differently according to their own self-confidence and pre-knowledge.

Most measurements have been developed and exist in an English version. There are few in the languages that most refugees speak, and translated versions are not always validated. Refugees are therefore often excluded from surveys and studies focusing on HL, and knowledge about HL among refugees is lacking. It is not recommended to use instruments in a language that the target group cannot speak, read or write since the target group may not understand or may misunderstand the content of the instrument, which could reduce the validity of the study [132]. Furthermore, it is unethical to give out an in-

strument in a language that the respondents do not fully master. Not understanding what is written can make people feel stupid and cause shame [133]. Translations can increase the number of people who respond to the instruments and enable cross-cultural comparison studies [132]. However, plain translation may not be sufficient, as people in different countries and from different cultures may interpret items differently.

The first Swedish HL instrument, the Swedish Communicative and Critical HL scale (the S-CCHL scale) [134], was developed in 2011. It is based on the JCCHL scale [131]. With this in mind, there was need for another Swedish instrument to assess FHL—partly to be able to study FHL alone and partly to be able to compare people’s FHL with their communicative and critical HL. Therefore, a second Swedish HL instrument, the Swedish FHL scale (S-FHL scale), was developed in 2012 [135]. Since then, the S-FHL scale has been translated into Arabic, Dari, English, Farsi, Somali and Sorani, while the short version of the European HL questionnaire (HLS-EU-Q16) [136] has been translated into Arabic, Dari, Farsi, Somali, Sorani and Swedish.

To summarize, HL is a complex and difficult concept to measure [89]. The use of different definitions, measurements and divisions of HL levels makes it complicated and sometimes impossible to compare results from studies that have used different measurements [64, 72]. HL measurements in use today can indicate HL levels but not give a complete answer concerning all HL skills in all kinds of contexts [89].

Aims

Overall aims

The overall aim of this thesis was to examine the distribution of HL levels in newly arrived Arabic-, Dari¹-, or Somali-speaking refugees in Sweden, and which sociodemographic characteristics are associated with inadequate HL in this group. Another aim was to investigate the extent to which the HL level is important for their experiences of the HEA, health seeking behaviour and health.

Specific aims

- To determine FHL and CHL levels among newly arrived refugees in Sweden.
- To investigate whether sociodemographic factors and long-term illness associates with FHL, among newly arrived refugees in Sweden.
- To investigate whether sociodemographic factors, long-term illness and FHL associates with CHL, among newly arrived refugees in Sweden.
- To explore newly arrived refugees' experiences of the communication during the HEA and the usefulness of that examination, and to examine the extent to which different FHL and CHL levels are associated with those experiences.
- To investigate whether CHL associates with self-perceived general health, psychological well-being, and having refrained from seeking healthcare, among newly arrived refugees in Sweden.

¹ Dialect of Persian language spoken in Afghanistan.

Methods

Design

Three of the studies are quantitative studies with a cross-sectional design. One of the studies is a qualitative study with an explorative design. An overview of the four studies conducted is presented in Table 1.

Table 1. Description of Studies I-IV.

Study	I	II	III	IV
Design	Quantitative cross-sectional	Quantitative cross-sectional	Qualitative explorative	Quantitative cross-sectional
Data collection	Questionnaire	Questionnaire	Focus group discussions	Questionnaire
Participants	NAR* having been offered an HEA, speaking Arabic, Dari, English or Somali (n = 455)	NAR having participated in an HEA, speaking Arabic, Dari, English or Somali (n = 360)	NAR having participated in an HEA, speaking Arabic or Somali (n = 28)	NAR (and family members allowed reunification) participating in courses in civic orientation, speaking Arabic, Dari or Somali (n = 513)
Data analysis	Chi square tests, Fisher's exact tests, Spearman's rank order correlation test, univariate and multivariate binary logistic regression, post-stratification	Chi square tests, Fisher's exact tests, Cronbach's alpha, univariate and multivariate binary logistic regression	Graneheim and Lundman's method for latent content analysis	Chi square tests, univariate and multivariate binary logistic regression
Background variables	Sex, age, education level, years of residence permit in Sweden, long-term illness, country of birth	Sex, age, education level, country of birth, support by interpreter, FHL, CHL	-	CHL, sex, age, education level, years with residence permit in Sweden, reasons for residence permit, participation in HEA, long-term illness
Outcome variables	Inadequate FHL, Inadequate CHL	Having experienced poor quality of communication; received little healthcare information; not having received any new knowledge; not having received any help	-	Poor general health, impaired psychological well-being, having refrained from seeking healthcare

*NAR = Newly arrived refugees

Settings and participants

Studies I and II

Studies I and II were conducted in language schools for immigrants (SFI) in four counties to gather participants from different geographic and demographic areas of Sweden. A strategic selection of SFI schools was made, based on the number of people who had received residence permits in each county as asylum seekers the previous year [137].

Eligible participants for Study I were adult refugees attending the classes the day each SFI school was visited, i.e., strategic selection was used. The inclusion criteria were:

- having been offered an HEA, speaking Arabic, Somali, Dari or English;
- being born outside the European Union and the Nordic countries;
- and having received a permanent residence permit as a seeker of asylum.

The chosen languages were the ones most widely spoken among refugees in Sweden at the time the study was planned. In total, 455 refugees were included in the study.

Eligible participants for Study II were the same as those for Study I, with one extra inclusion criterion, which reduced the total study population: the participants should have participated in an HEA. In total, 360 refugees were included in Study II.

The characteristics of the study populations in Studies I and II were similar. There were slightly more men than women. The average age was about 35 years and most of the participants were born in Somalia, Iraq, Syria or Afghanistan. Most of them had studied seven years or more in school, and the majority had received a residence permit in Sweden one to two years previously. About half of the participants reported less than good health.

Study III

Study III was conducted in Stockholm, Gothenburg and Malmö, the three largest cities in Sweden, to gather participants from different geographic areas.

Eligible participants for Study III were adult refugees participating in SFI and in courses in civic orientation, who were interested in taking part in a focus group to share their experiences of the HEA.

The inclusion criteria were:

- speaking Arabic or Somali fluently;
- having received a permanent residence permit as a seeker of asylum;
- and having participated in an HEA in the last three years.

In total, 28 refugees were included in the study. There were slightly more men than women, the mean age was 40 years (range 24-67 years) and most were born in Syria or Somalia. Education levels were fairly uniformly distributed and varied from zero to more than 12 years of education. Most had received a residence permit in Sweden one to two years previously. Altogether, they had participated in HEAs in about 15 different locations in various geographical regions in Sweden, most with an interpreter present.

Study IV

Study IV was conducted in courses in civic orientation in and around Stockholm, the capital of Sweden. Eligible participants were adult refugees, or family members allowed reunification with a refugee, attending the civic orientation the first day of the course. That is, consecutive selection was used.

The inclusion criteria were:

- speaking Arabic, Dari or Somali
- and participating in a course in civic orientation.

In total, 513 refugees were included in the study. Most were born in Syria and most were men. The mean age was 38 years. The majority had limited CHL and about two out of five had an academic degree. Almost everyone had received a residence permit in Sweden one to two years previously, most being granted asylum. The majority had participated in an HEA and about one out of four had reported a long-term illness.

Procedure

Studies I and II

Studies I and II are both based on the self-report paper-and-pencil questionnaire Experiences and Opinions of Health and Health Check-ups for Asylum Seekers. The questionnaire intends to collect information about refugees' experiences and perceptions of the health examination for asylum seekers. It consists of 60 questions, including both questions used in previous research [78, 138] and new questions developed by the research team.

In the development of the new questions focusing on the HEA, an exploratory pre-study was conducted. It was based on focus group discussions and individual interviews with refugees sharing characteristics with the planned study population, and on dialogues and a workshop with key people working with refugees [139]. Fifty refugees participated in nine focus groups, and four refugees were individually interviewed. Mostly, the participants' native language (Arabic, Dari or Somali) was used. Seven key people participated in the workshop and 11 gave their input through individual communication with the researchers.

One purpose of the pre-study was to get a first view of refugees' experiences and perceptions of the HEA. Other purposes were to identify difficulties and possibilities associated with a larger quantitative survey and more extensive qualitative studies, and to collect knowledge for developing questions and response alternatives, as well as appropriate discussion guides for them. In addition, knowledge about the HEA and how it is experienced was collected during eight focus group discussions with in total 41 people working with the HEA in healthcare and at the Migration Board [38].

No HL instrument in the languages of the target groups existed when Studies I and II started. To measure functional health literacy, translation of the S-FHL scale [135, 140] was seen to be an appropriate solution. To measure CHL, the original plan was to translate the S-CCHL scale [134]. However, during the development of the S-CCHL scale, a new HL instrument, the HLS-EU-Q47 and its short form, the HLS EU-Q16 was developed in Europe [128, 136]. It was decided to use the HLS EU-Q16 instead, because it was more comprehensive and had more concrete items, and because the use of that instrument facilitated comparing results to other populations in Europe.

When a first version of the full questionnaire had been decided, the whole questionnaire was translated into Arabic, Dari, English and Somali following guidelines for the translation of instruments [132], i.e., it was translated, back-translated and pre-tested. Concept equivalence [132, 141] was sought to secure that the questions have the same meaning in all language versions.

Key people, in the form of bilingual language supporters sharing culture/country of origin with the study population, also gave feedback on the translations. The intention was to make the questions in the questionnaire as clear and understandable as possible for the study population, including people with various education levels and who spoke different dialects. When finding questions unclear or difficult to understand, the language supporters were asked to suggest alternative formulations. If several words could be used for the same thing, e.g., in different dialects, language supporters from different regions,

speaking different dialects, were consulted in order to settle on a phrasing that would work for most people speaking the language.

All language versions of the new questions, as well as the questions that had not been used among refugees before, were thereafter tested on four to six native speakers of the language. Owing to limited time and resources, it was not possible to conduct reliability testing through test-retest and interviews with professionals speaking the languages of the translated versions as their native language.

The persons interviewed about each translated instrument version were selected so as to share characteristics with the intended study population (newly arrived refugees). Based on the interview results, the translated S-FHL scale and HLS-EU-Q16 had to be slightly changed. Specifically, it was realized that full sentences would have to be written out for all items.

Furthermore, “don’t know” was added as a response category in the HLS-EU-Q16, since not all people have been in all the situations the items describe. Originally, the HLS-EU-Q16 is used orally and “don’t know” is not given as an option when the answer categories are read out loud [136]. However, the interviewer can tick the alternative “don’t know” if the respondent spontaneously answers that they do not know. The idea was that adding a “don’t know” category should decrease the risk of random answers, thus providing a more reliable overall HL score.

Items and response alternatives included in the S-FHL and HLS-EU-Q16 are presented in tables 2 and 3.

Table 2. Items and response alternatives in the S-FHL.

Q1. Do you think that it is difficult to read health information because the text is difficult to see (even if you have glasses or contact lenses)?
Q2. Do you think that it is difficult to understand words or numbers in health information?
Q3. Do you think that it is difficult to understand the message in health information?
Q4. Do you think that it takes a long time to read health information?
Q5. Do you ever ask someone else to read and explain health information?
Response alternatives: never, seldom, sometimes, often, always

Table 3. Items in the HLS-EU-Q16 that was used.

<p>Q1. How easy/difficult is it for you to find information on treatments of illnesses that concern you?</p> <p>Q2. How easy/difficult is it for you to find out where to get professional help such as doctor, pharmacist or psychologist when you are ill?</p> <p>Q3. How easy/difficult is it for you to understand what your doctor says to you?</p> <p>Q4. How easy/difficult is it for you to understand your doctor's or pharmacist's instruction about how to take a prescribed medicine?</p> <p>Q5. How easy/difficult is it for you to judge when you may need to get a second opinion from another doctor?</p> <p>Q6. How easy/difficult is it for you to use information the doctor gives you to make decisions about your illness?</p> <p>Q7. How easy/difficult is it for you to follow instructions from your doctor or pharmacist?</p> <p>Q8. How easy/difficult is it for you to find information on how to manage mental health problems like stress or depression?</p> <p>Q9. How easy/difficult is it for you to understand health warnings about behaviour such as smoking, low physical activity and drinking too much?</p> <p>Q10. How easy/difficult is it for you to understand why you need health screenings such as breast exam, blood sugar test or blood pressure?</p> <p>Q11. How easy/difficult is it for you to judge whether the information on health risks in TV, internet or other media is reliable?</p> <p>Q12. How easy/difficult is it for you to decide how you can protect yourself from illness based on information in newspapers, leaflets, internet or other media?</p> <p>Q13. How easy/difficult is it for you to find out about activities (such as meditation, exercise, walking and pilates) that are good for your mental well-being?</p> <p>Q14. How easy/difficult is it for you to understand advice on health from family members or friends?</p> <p>Q15. How easy/difficult is it for you to understand information in the media (such as internet, newspapers and magazines) on how to get healthier?</p> <p>Q16. How easy/difficult is it for you to judge which everyday behaviour (such as drinking and eating habits, exercise) is related to your health?</p> <p>Response alternatives: very difficult, fairly difficult, fairly easy, very easy, don't know.</p>

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On the day of the data collection, a researcher together with some language supporters visited the school. The language supporters first informed the students in the schools about the research project and that participation was voluntary. The questionnaire was then distributed on site in a separate classroom to those who fulfilled the inclusion criteria and consented to participate. All eligible participants agreed to take part in the study. Refugees who had difficulties reading or writing were supported by language supporters who read aloud and helped them fill in the questionnaire.

Study III

Study III is based on qualitative data collected from seven focus group discussions.

The researcher contacted schools offering SFI or civic orientation, by email and telephone, describing the study. These arenas were chosen because most of the study's target group takes part in those activities to obtain financial compensation under the Swedish establishment act [142]. Teachers in the schools that had agreed to participate then informed their students about the study and distributed information letters and notice of interest forms in Somali and Arabic. The students were also invited to disseminate information about the study to other potential participants outside the classroom.

The notice of interest form included questions about gender, age, education level and participation in the HEA. It was collected in order to create homogenous focus groups and to reduce the risk of creating groups inhibiting participants from expressing themselves due to possible negative power relations [143, 144]. Foremost, men and women, and participants with very low and very high levels of education, were kept apart. Zero to nine years of education was classified as low, ten years or more as high. This division was made based on the education levels of the participants available.

Students who volunteered to participate and gave contact details were contacted again, given information about the study in Arabic or Somali, and were asked for informed consent either by the teacher or by a moderator. In total, seven focus group discussions took place, four in Arabic and three in Somali, all led by female moderators. Characteristics of each focus group are presented in table 4.

Table 4. Characteristics of focus groups.

Language	Sex	Low educated	High educated
Arabic	Men	1 group	1 group
	Women	1 group	1 group
Somali	Men	1 group	1 group
	Women	1 group	

According to recommendations of key persons in the target groups and experiences from previous cross-cultural studies [145], it is possible for women to hold discussions in groups with either men or women, but men could not always hold discussions in groups with women. Three bilingual moderators were used, all with proper academic and cultural competencies according to

recommendations for cross-language qualitative research [143, 146]. Two different Somali-speaking moderators were used for reasons unrelated to the study—the first moderator took ill. All three followed a similar discussion guide and were given a list with examples of probing questions to use (see the Measurements section). In addition, the moderators were given a guide with items about which the participants must be informed before the focus groups started, for example, the purpose of the study and how data would be used, informed consent, and voluntariness. A method chapter from a handbook in focus group research about moderating skills [143] was also given out. As main researcher in the study, I took part in all focus groups as an observer.

The focus group discussions were recorded digitally, and each lasted about 60 minutes. They took place in a classroom in the same building where participants studied SFI or civic orientation, or in a nearby building. During the focus group discussions coffee/tea and something to eat (a small sandwich and fruits) were offered. After each discussion, the moderator gave me, as observer, an outline of what the participants had talked about. Thereafter we together discussed what could be improved methodologically in the following focus group discussions.

The Arabic audio files were transcribed and translated simultaneously into Swedish by the Arabic moderator having qualified translation skills. The Somali audio files were transcribed and translated simultaneously into Swedish by an external translator with previous experience of moderating and transcribing focus groups in the health field. A transcript protocol by McLellan [147] was used, and concept equivalence [132, 141] was pointed out as more important than translating the audio files word by word, to ensure that all transcripts were given the same structure and level of detail. Independent bilingual and bicultural persons familiar with the research area checked 10% of each transcript for accuracy, to control for the risk of interpreter bias [141]. There were some smaller differences, but nothing that really mattered.

Study IV

Study IV is based on selected questions from the self-report paper-and-pencil questionnaire Evaluation of the Civic Orientation for Newly Arrived Refugees. The purpose of the questionnaire was to map the characteristics of the participants and their need for health information at the beginning of civic orientation courses given in Stockholm, the largest city in Sweden. These courses are offered to refugees after they receive a residence permit, and to their family members when allowed family reunification.

New questions constructed for the questionnaire were translated into Arabic, Dari and Somali following guidelines for the translation of instruments [132]; i.e., translation, back translation and cognitive interviews were performed, in the same way as in Studies I and II. However, this time cultural mediators working in the civic orientation were consulted for feedback on the questionnaire. They are bilingual and bicultural in the same way as the language supporters employed in studies I and II. Also, they are the ones who really know the study population's skills and abilities, working with them on a group level in civic orientation on a daily or weekly basis.

All language versions of the new questions were tested in three or four cognitive individual interviews in each language before the questionnaire was finalized. Questions reused from Studies I and II were not tested again.

Information about the evaluation programme for the civic orientation (which the study was a part of), about the questionnaire, and that participation was voluntary, was given in writing in the refugees' native language together with the course invitation letter. On the first day of the course in civic orientation, a researcher together with a language supporter visited each group to collect data. The language supporter first informed the participants in their native language about the research project and that participation was voluntary. The questionnaire was then distributed on site and those who consented to participate filled in the questionnaire. Most eligible participants agreed to take part in the study. On average, less than one refugee in each group refused to participate in the study, and the reason why they did so is unknown. Participants having difficulties reading or writing were supported by language supporters who read aloud and helped them to fill in the questionnaire.

Measurements

Study I

Eleven questions from the questionnaire Experiences and Opinions of Health and Health Check-ups for Asylum Seekers were used in Study I:

- country of birth,
- sex,
- age,
- education level,
- years of residence permit,
- religion,
- self-assessed general state of health,
- self-reported long-term illness,
- and healthcare in the past

were used to analyse the sociodemographic and health-related characteristics of the study population. The S-FHL and HLS-EU-Q16 scales, which were included as questions in the questionnaire, were used to measure functional and comprehensive health literacy, respectively.

Study II

Nineteen questions from the questionnaire Experiences and Opinions of Health and Health Check-ups for Asylum Seekers were used in Study II. Three of the nine sociodemographic and health-related questions used in Study I were excluded: religion, long-term illness, and healthcare in the past. Instead, the two characteristics “time since having participated in an HEA” and “support of interpreter” were included.

Furthermore, the adapted versions of the S-FHL scale and HLS-EU-Q16 used in Study I were also used in Study II. However, owing to many missing values on items in the HLS-EU-Q16, many participants (36 %) did not get an overall sum score for CHL. An alternative analysis method was thus used, which allowed estimation of CHL even if the participant had missing values on many items. The method is described in more depth in article II.

In addition, nine questions were used to assess four dependent variables describing the participants’ experiences of communication during the HEA, and of its usefulness. The variable *Quality of communication* was based on four questions examining different aspects of communication during the HEA. Perceived usefulness of the HEA was measured by three questions contributing to the variable *Receiving healthcare information*, and by the two single-question variables *Receiving new knowledge* and *Receiving help*.

A sum score for *Quality of communication* was computed by assigning values 1 to 3 to the response alternatives “no”, “partly” and “yes”, respectively, yielding a maximum total score of 12. For *Receiving healthcare information*, the two response alternatives “yes” and “no” were assigned values 1 and 2, respectively, yielding a maximum total score of 6.

The variable *Receiving new knowledge* was based on one question: whether or not the participant had received any new knowledge that can contribute to improving health. *Received help* also consisted of one question: whether or not the participant had received any help with their health problems. The response alternatives “no”, “partly” and “yes” were for both questions assigned values from 1 to 3, respectively. The response alternative “don’t remember” was for all questions treated as missing and assigned value 0. Full questions used for the dependent variables are presented in Table 5.

Table 5. Questions used for the dependent variables in Study II.

Dependent Variables	Questions
Quality of communication*	<p>Did you understand what you were told when you did the health check-up for asylum seekers?</p> <p>Could you talk about the health problem that you had when you did the health check-up for asylum seekers?</p> <p>Could you ask questions that you had when you did the health check-up for asylum seekers?</p> <p>Did you get answers to the questions you asked when you did the health check-up for asylum seekers?</p>
Receiving healthcare information**	<p>Did you get information about...</p> <p>... what rights asylum seekers have to health and medical care in Sweden, when you did the health check-up for asylum seekers?</p> <p>... where you can go if you become sick in Sweden, when you did the health check-up for asylum seekers?</p> <p>... where you can go for help in Sweden if you feel mentally unwell (for example, if you are very sad, stressed or worried), when you did the health check-up for asylum seekers?</p>
Receiving new knowledge*	<p>Did you receive new knowledge that can contribute to improve your health, when you did the health check-up for asylum seekers?</p>
Receiving help*	<p>Did you get help for the health problem that you had, when you did the health check-up for asylum seekers?</p>

* Response alternatives were “yes”, “partly”, “no” and “don’t remember”

** Response alternatives were “yes”, “no” and “don’t remember”

Study III

On the basis of the knowledge and experiences from the two pre-studies [38, 139], the authors developed a discussion guide for the moderators, aiming to ensure that the most important issues concerning the experience of the HEA would be discussed in all the focus groups. Examples of questions in the discussion guide are given in table 6. The guide was translated into Arabic, tested in the first focus group, and then used in a rather similar form throughout the study. Only some reordering of the questions and small vocabulary changes were made in order to clarify and make it easier for the participants to fully understand and discuss the questions asked by the moderator. Examples of probing questions given to the moderators are presented in table 7.

Table 6. Examples of questions in the discussion guide.

-	What are your experiences from the health examination for asylum seekers?
-	How did the communication work when you participated in the health examination for asylum seekers?
-	How did you experience the information you received when you participated in the health examination for asylum seekers?
-	How do you experience the benefits of participating in the health examination for asylum seekers?

Table 7. Examples of listed probing questions.

-	Could you explain further?
-	Can you give an example?
-	Which other experiences do you have?
-	Interesting, could you tell us more about it?
-	In which way was it bad/good?
-	Do you all agree with this? Why/Why not?

Study IV

In Study IV, 12 questions from the questionnaire Evaluation of the Civic Orientation for Newly Arrived Refugees were selected for multivariate analysis: Three questions were treated as dependent variables, one question as an independent variable, and eight questions divided into three groups were treated as potential confounders.

The dependent variables were:

- *General health*, measured by the question "How do you assess your overall health status?" [148].
- *Psychological well-being*, measured by the shortest form of the General Health Questionnaire (GHQ12) [149].
- *Having refrained from seeking healthcare*, measured by the question "In the past three months, have you felt a need for help with health problems, but have not sought healthcare?" [150-152].

CHL, treated as an independent variable, was measured using the Swedish version of the short European HL questionnaire (HLS-EU-Q16) [136], but a slightly modified version compared to the one used in Studies I and II. Unlike in the previous studies [153, 154], the response alternative "don't know" was not used. This decision was made based on the experience of many missing values complicating the calculation of the overall sum score of HL. This also made the questionnaire more similar to the original version of the instrument [136] in which the "don't know" alternative is only used if the respondent (questioned verbally) does not answer any of the four given response alternatives.

Demographic data used were:

- country of birth,
- sex,
- age
- and education level.

Migration-related data used were:

- years with a residence permit in Sweden,
- reason for residence permit,
- and having participated in the HEA.

Long-term illness was measured by the question "Do you have any long-term illnesses, problems after an accident, any functional difficulties or other long-term health problems?" [155]. All eight questions were the same as those used in Studies I and II.

In addition, the questionnaire included a question about the reasons for having refrained from seeking healthcare, asking the participant to select one or more suggested reasons from a list. This question was only analysed and reported descriptively; it was not included in the multivariate analysis.

Data analysis

Quantitative studies (Studies I, II and IV)

Statistical analyses were conducted using the Statistical Package for the Social Sciences (SPSS) version 21.0 (Chicago, IL, USA). Chi-square tests—or Fisher’s exact tests when the expected cell count was less than 5 in 20% of the cells or more—were used in Studies I, II and IV to test for differences in HL levels between groups.

In Study I, groups based on various sociodemographic and health-related characteristics were compared. In Study II, a comparison was made between groups reporting different experiences of various aspects of the HEA. In Study IV, groups were defined by differences in general health, psychological well-being, and whether they had refrained from seeking healthcare.

Spearman’s rank order correlation test was used in Study I to assess associations between CHL, FHL, and other characteristics.

Univariate and multivariate binary logistic regression analyses were used in Studies I, II and IV. The results are presented as crude (COR) and adjusted odds ratios (OR) with 95 % confidence intervals (CI) and p-values. A p-value of < 0.05 was considered statistically significant, and all analyses were two-sided.

In Study I, binary logistic regression analyses were performed to assess the extent to which various independent covariates predict inadequate FHL/CHL as dichotomized outcome variables. Three models with different numbers of characteristics were assessed. Furthermore, binary logistic regression analyses were used to estimate non-response bias regarding lack of FHL or CHL level. Post-stratification by Carlin et al.[156] was used to account for non-response bias.

In Study II, binary logistic regression analyses were performed to assess associations between FHL and CHL as independent variables, and the four dependent variables focusing on different experiences of the HEA. In preparation for the analysis, each dependent variable was dichotomized into a higher and a lower group suggested by the data. Scores equal to or higher than the median were assigned to the high group; scores lower than the median to the low group, as shown in table 8.

Table 8: Dichotomization of dependent variables in study II.

Dependent Variable	High Group	Low Group
Quality of communication	Sum score ≥ 11 (perceived high quality)	Sum score < 11 (perceived low quality)
Receiving healthcare information	Sum score ≥ 5 (received much information)	Sum score < 5 (received little information)
Receiving new knowledge	Score ≥ 2 (received some new knowledge)	Score < 2 (received no new knowledge)
Receiving help	Score ≥ 2 (received some help)	Score < 2 (received no help)

Binary logistic regression analyses were also used in Study II to examine whether the results from the logistic regression analyses remained the same when including only participants with a true sum score of CHL, excluding the participants with missing data for which an alternative scoring method had been used. In addition, binary logistic regression analyses were performed to test the robustness of the results to using alternative cut-offs for the four dependent variables.

In Study IV, binary logistic regression analysis was performed to examine associations between CHL, potential confounding factors and the dependent variables. In preparation for the analysis, each dependent variable was dichotomized in the same way as in previous studies [26, 27, 149, 155], and summarized in table 9.

Table 9: Dichotomization of dependent variables in study IV.

Dependent Variable	High Group	Low Group
General health	Good (good or very good)	Less than good (fair, poor or very poor)
Psychological well-being	Not impaired (sum score > 2)	Impaired (sum score ≤ 2)
Refrained from seeking healthcare	Not refrained from seeking healthcare	Refrained from seeking healthcare

In the multivariate analysis, the confounding variables were inserted stepwise, manually. Three models, with different numbers of possible confounding variables, were evaluated for each of the three dependent variables.

Qualitative study (Study III)

When analysing the qualitative data collected in study III, Graneheim and Lundman's method for latent content analysis [157] was used, and served as an analytical framework in order to find the latent meaning of the data. The analysis was carried out manually in three phases, in which two of the authors (JW and LM) were most active. Both are Swedish-born women without a migrant background and both have extensive knowledge, practical experience and experience from research in the field of health promotion and HL. Reflexivity was considered in the way that preconceptions were acknowledged as a factor that could influence the interpretation of the data.

The first phase started when all data had been collected. The authors independently read each transcript, and distinguished, condensed and coded meaning units. In the few cases when ambiguities in the transcripts were found, the moderator was contacted for a clarification. When all the features of interest in the data had been coded, those were compared and discussed in order to identify the latent content. Examples of the analytical process are given table 10.

Table 10. Examples of the analytical process*.

Meaning unit	Condensed meaning unit	Codes	Sub-category	Category
A2P1: They gave us no information...	HEA did not	HEA takes	Does not focus	Causes
A2P3: They took information.	give any infor-	more than	on the individ-	feelings of
A2P1: ...They took information.	mation, it just	it gives.	ual	disappoint-
They gave us none.	took.			ment
A2P5: neither did they say results.				
We do not know				
A2P1: No information and no advice.				
They took information and				
asked what we had for trouble.				

*First capital letter indicates focus group; second capital letter indicates participant.

The codes were sorted into categories in the second phase. Several preliminary categories were tried, and irrelevant codes were discarded. Discussions were held about the content of and the relationships between sub-categories and categories, about similarities and differences within and between all the categories, and about how well they matched with the raw data. Categories and sub-categories were rearranged and discussed several times until they were distinctly separated. Thereafter, a description of the content of each category and sub-category was formulated. To ensure that they were based on the empirical experiences from the focus group discussions, a constant exchange was made between the original transcripts and the emerging categories. This process continued until the content of each category had stabilized. Finally, the descriptions were repeatedly edited to further clarify and distinguish categories. A flowchart of phase 2 is presented in figure 2.

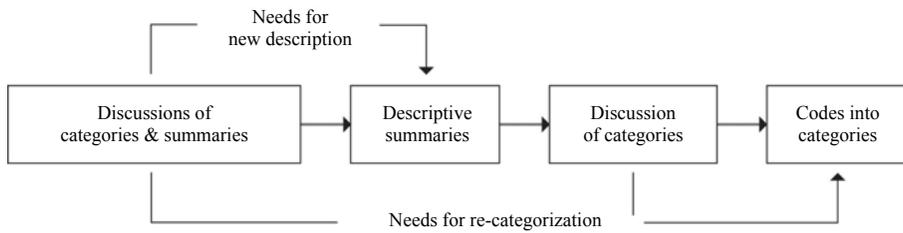


Figure 2. Flowchart of phase 2.

In the third phase, the underlying meaning of all the categories were discussed in order to formulate a common theme [157]. Quotes giving examples of how participants expressed themselves were finally chosen to illustrate and verify each category. To check for the accuracy of the interpretations and the trustworthiness of the results, two of the moderators reviewed the final results, and both agreed on them.

Ethical considerations

All studies were performed in accordance with the medical research ethical standards of the Declaration of Helsinki [158]. Ethics approval at the Regional Committee of Clinical Investigation in Uppsala was sought for Studies I, II and III, but the committee’s judgments were that approval was not deemed necessary or applicable according to Swedish law (DNB 2012:506, DNB 2013:446). In Studies I and II, the data collections were performed anonymously, leaving no possibility for individual identification. Study IV was approved by the Regional Committee of Clinical Investigation in Uppsala, Sweden (DNB 2014:526).

In all studies, the participants were informed verbally and in writing that participation was voluntary and that they could withdraw at any time without any negative consequences. All participants gave their informed consent. Returning a completed questionnaire was regarded as providing informed consent. Written consent was not used because it requires collection of the name, which many people, especially refugees, do not want to give due to mistrust of authorities.

Language supporters and translated questionnaires were used in Studies I, II and IV to secure that potential participants with another native language than Swedish understood all information and understood the questionnaire itself. In addition, these measures increased the possibility for all refugees to participate, whether they were well-educated or analphabets. The latter group is underrepresented in research. On the other hand, this might also have caused pressure on the presumable participants to take part in the surveys.

The collection of data during the participants' ordinary course times may have reduced their feeling that it was voluntary to take part in the study, especially since participation in SFI and civic orientation is linked to economic compensation [142]. To reduce this risk, in Studies I and II, information was given that those who did not participate should work with education tasks given by their teacher, during the time those who wanted to participate filled in the questionnaire.

Furthermore, many in the target group are not familiar with scientific studies based on population surveys. In many countries, authorities register and use data without consent, which is something that the participants may know or have experienced. To reduce this risk of misinterpreting the study's intention, information about the study and its voluntariness was given in the target group's own languages, and they could ask questions in their own language if something was unclear.

Overall, the use of language supporters and the use of translated questionnaires increased the willingness to participate in the study. Many participants expressed that they would not have answered the questionnaire if Swedish-speaking researchers alone performed the data collection, as they do not trust authorities but do trust and feel secure when their "own" countrymen are involved in the research project. Furthermore, many participants expressed that they were very happy to be asked about their health and experiences in their own language, contributing to better health information and health examinations for future refugees.

To ensure that the results of the studies, i.e., the participants' perceptions and experiences, will benefit society, the results of Studies I and II have been disseminated by means of reports and scientific papers and at scientific conferences and lectures directed to staff in healthcare, in the civic orientation and from the Swedish Migration Board, as well as to students in various health-related programmes. All SFI schools where data were collected have also been sent a report and an invitation to share the results with their students. In addition, the results are disseminated through the Swedish health literacy webpage www.halsolitteracitet.se. Results from Studies III and IV will be distributed in similar ways as soon they are published.

Another critical ethical aspect is the confidentiality for analphabets taking part in Studies I, II and IV. In some groups in which there were many analphabets, language supporters sometimes helped more than one participant at the same time. This may have led to “censored” answers and a reduced number of responses from participants not wanting to share them with others. People with limited HL skills often hide their weaknesses and shortcomings as they are often linked to shame [65, 133]. Another reason could be that participants, due to their culture, could be very humble and grateful and not want to complain about a system or situation in a country in which they have received a permanent residence permit [2]. Participants who answered verbally were always informed about the voluntariness again, that there did not exist any right or wrong answers and that their specific experiences and answers were important for improving the HEA/the civic orientation.

Main results

Study I

The majority of the participating refugees had limited FHL and/or CHL (Study II, table 1). About 60 % had inadequate FHL and about 20 % had problematic FHL, i.e., about 80 % had limited FHL. About 27 % had inadequate CHL and about 34 % had problematic CHL, i.e., about 60 % had limited CHL. About one out of three had reported some long-term illness and almost half had less than good health and/or had visited health care during the previous three months.

Chi-square tests showed that there were statistically significant group differences with respect to FHL levels and the sociodemographic variables of age, years of residence permit and education level (Study I, table 2). In addition, the tests showed that there were no statistically significant group differences with respect to CHL levels and any of the examined sociodemographic variables. Results from Spearman's correlations analysis confirmed the results from the chi-square tests but also showed that both inadequate FHL and inadequate CHL were associated with having a long-term illness and with poor self-assessed health (Study I, table 3).

However, when adjusting for several sociodemographic variables (as well as for having some long-term illness) in a binary multivariate logistic regression analysis, the only remaining statistically significant associations with having inadequate FHL were having low education (OR:2.25, CI 95% 1.20-4.20) and being born in Somalia as compared to Iraq (OR:2.89, CI 95% 1.28-6.53) (Study II, table 4). A similar multivariate logistic regression analysis assuming CHL to be the dependent variable showed no statistical significant associations with sociodemographic variables. Having inadequate FHL was the only variable that showed a statistically significant association with having inadequate CHL (OR: 3.97, CI 95% 1.23-12.89) (study II, table 4).

Study II

The majority of the participating refugees had limited FHL and/or limited CHL. About 60% had inadequate FHL and about 19 % had problematic FHL, i.e., about 80 % had limited FHL. About 42 % had inadequate CHL and about 31 % had problematic CHL, i.e., about 70 % had limited CHL. Slightly more than two out of five had less than good health, i.e., rated their health as fair, poor or very poor. In the HEA, 28 % experienced a poor quality of communication. Having received little information about healthcare, little new knowledge, and no help was experienced by 31 %, 34% and 23%, respectively. (Study III, table 2).

No associations were found between FHL levels and the examined experiences of the HEA (Study II, additional file 4). However, associations were found between CHL levels and all the examined experiences of the HEA. The results remained statistically significant when adjustment was made for several variables in the multivariate logistic regression analysis.

Having inadequate as compared to sufficient CHL was associated with having experienced the quality of the communication in the HEA as poor (OR: 9.64, CI 95 %: 3.25–28.58). Among the other independent variables included in the model, not having had support by an interpreter also showed a statistically significant association with the experience of a poorer quality of communication (OR: 2.35, CI 95% 1.00-5.48).

Having inadequate or problematic, as compared to sufficient, CHL was associated with the experience of having received little healthcare information (OR: 6.54, CI 95 % 2.45-17.47 and OR: 3.39, CI 1.27-9.05, respectively). Among the other independent variables included in the model, not having had support by an interpreter (OR: 2.49, CI 1.08-5.75) was also found to be significantly associated with the experience of receiving little healthcare information.

Having inadequate or problematic, as compared to sufficient, CHL was associated with the experience of not having received any new knowledge that could contribute to improvement of one's own health (OR: 7.94, CI 95 % 3.00–21.06 and OR: 3.71, CI 95 % 1.45-9.50, respectively). Among the other independent variables included in the model, being a woman (OR: 0.33, CI 95% 0.16-0.68) was also significantly associated with the experience of not receiving any new knowledge.

Having inadequate or problematic, as compared to sufficient CHL, was associated with the experience of not having received any help with health prob-

lems (OR: 8.07, CI 95 % 2.50–26.07 and OR:3.33, CI 95 % 1.02-10.86, respectively). No statistically significant associations were found with any other independent variable.

In summary, different factors are associated with experiences of poor communication and of not having received healthcare information, new knowledge or help during the HEA. Limited CHL is the factor with the highest OR for reporting these negative experiences.

Study III

One overarching theme - beneficial and detrimental – and three core categories were found: that HEA gives some good; that it causes feelings of insecurity; and that it causes feelings of disappointment (Figure 3).



Figure 3. Overview of themes, categories and sub-categories in study III.

The category “gives some good” consisted of two sub-categories describing the HEA as something that “gives support and relief” and “cares on a personal level”. Participants experienced that the HEA gives support by giving help, either directly or through referrals, for identified health problems. It also gives out useful health information. In addition, participants experienced that the HEA gives relief by informing about one’s correct health status, information that could also be used to show society that they are not at risk for ill health.

The HEA was experienced as caring on a personal level, because asking questions and sharing personal health problems were encouraged, and because support by interpreters was offered. In addition, the HEA offered more extensive examinations and information when asked for, and its staff proved to be friendly and understanding.

“After a health examination, you get rid of a lot of worry that you’ve had and find out that everything is okay” S2 (P1)

“I told them that I had a knee injury...and they sent me right away to get sessions with a physical therapist...” A3 (P5)

“They were cooperative and even asked me whether there was something I wanted to bring up...I think they treated me in a good way” A4 (P1)

The category “causes feelings of insecurity” consisted of two sub-categories describing the HEA as something that “lacks clarity” and that “does not give protection”. The HEA was experienced as lacking clarity, by giving too little tailored information for its specific target group, about its purpose, and about the contents of the examination. In addition, the use of low-qualified interpreters was experienced as leading to unsatisfactory communication, poor trust and unmet health needs. The HEA was experienced as causing feelings of insecurity, as it does not fully protect from ill health, is not given to everyone directly upon arrival in Sweden, and gives little information about how to protect oneself from other newly arrived refugees’ poor health. In addition, the HEA gives little information about how to prevent common diseases in the new country. Another way the HEA was experienced to cause feelings of insecurity was by partly using personal testimonies to identify ill health, testimonies which must not necessarily be true.

“It was hard to read the information we got on a paper. First, the language is hard to understand. The time you put into trying to understand is hard in itself...” S1 (P2)

“I decline some things. She was there for half an hour and then I continued in English with her (the doctor) ...there were some private things I didn’t want to say when she (the interpreter) was there” (A3, P3)

“I felt that (the HEA) should have been given much earlier...I lived with a family, in a house with many family members. If I’d had a disease without visible symptoms it would have spread before the examination.” (A4, P3)

The category “causes feelings of disappointment” consisted of two sub-categories that describe the HEA as something that “does not fulfil the image of a health examination” and “does not focus on the individual level”. The HEA was experienced not to fulfil the image of a health examination as it does not correspond to previous experience, knowledge, or beliefs about what is included in such examinations. Neither was the HEA experienced as caring about personal health problems, such as mental health problems that were brought up. Unmatched expectations, in turn, lead to disappointment. The HEA was experienced not to focus on the individual as it took more information from the participant than it gave in return. In addition, the HEA has a pre-defined focus on specific diseases and shows no interest in other personal health issues.

“They say it’s a general examination and then they should look at the whole body. Legs, nerve...everything. They just took blood and that was it. They should have a more thorough examination that they make, in different areas.” (A2, P4)

“Yes, when I was at the doctor he asked me questions like that and that and that, have you heard that? Then I said no and the doctor was just quiet” (S3, P4).

“But, I think they should answer regardless of whether it’s (the test) positive or negative. Because you think the whole time that the letter got lost, or was sent to the wrong address, so you think about it until you get to know your results.” (A2, P1)

More quotes illustrating each subcategory are presented in Study III, tables 4-6.

Study IV

About two out of five estimated their overall general health as less than good, and chi-square tests indicated that, the lower the CHL, the poorer the general health (Study IV, table 2). This association remained statistically significant when adjusting for several potential confounding variables (Study IV, table 3). Other factors that were found to be statistically significantly associated with less than good health were old age, low education level and having reported a long-term illness (Study IV, table 3). The OR for having less than good health was highest for those with long-term illness (OR: 6.93, CI 95% 3.87-12.41) or who were 45 years or older (OR: 5.26, CI 95 % 2.02-13.69). The OR for having poor health was marginally higher for those with inadequate CHL than for those with low education level (Inadequate CHL OR: 2.93, CI 95%: 1.58-5.42 vs. 0-6 years of education OR: 2.20 95% CI 1.01-4.77, and 7-12 years of education OR: 1.23, 95 % CI 0.71-2.12).

Just over a third of the respondents were classified as having impaired psychological well-being, and chi-square tests indicated that, the lower the CHL, the greater the percentage of respondents had impaired psychological well-being (Study IV, table 2). This association remained statistically significant when adjusting for several potential confounding variables (inadequate CHL OR: 4.86 CI 95%: 2.74-8.66 and problematic CHL OR: 2.35 CI 95% 1.27-4.33) (Study IV, table 4). No other potential confounder included in the model was significantly associated with having impaired psychological well-being.

Just over a third reported having refrained from seeking healthcare in the most recent three months, and chi-square tests indicated that, the lower the CHL, the more respondents reported having refrained from seeking healthcare (Study IV, table 2). When adjusting for all potential confounding variables, the association remained significant only for inadequate CHL (Study IV, table 5). Other factors that were in the full model statistically significantly associated with having refrained from seeking healthcare were low education level, having participated in an HEA, and having reported a long term-illness (Study IV, table 5). The OR for having refrained from seeking healthcare was highest for those with long-term illness (OR: 3.96, CI 95% 2.25-6.98), thereafter for those not having participated in an HEA (OR: 2.45, CI 95% 1.37-4.37) and/or were more educated (12 years or more of education OR: 2.44, CI 95% 1.11-5.36, and 7-12 years of education OR: 2.38, CI 95% 1.09-5.21). The OR for people with inadequate CHL having acted in this way was slightly lower (OR 2.12, CI 95%: 1.20-3.73). In addition, the descriptive statistics showed that the most common reasons for having refrained from seeking healthcare reported by the refugees themselves were: language problems (40%); did not think that help could be obtained (24%); would wait for a while (19%); and did not know where to go (19%) (not presented in any table).

In summary, many factors are associated with having reported less than good health, impaired psychological well-being and having refrained from seeking healthcare. The ORs of having poor health status or having refrained from seeking healthcare are not the highest for those with limited CHL, but it does matter.

Discussion

The overall aims of this thesis were to examine the distribution of HL levels among newly-arrived refugees and to examine which sociodemographic characteristics associate with inadequate HL in this group. Other aims were to examine the extent to which the HL level is important for refugees' experiences of the HEA, for their perceived health, and for their health-seeking behaviour.

The thesis' main results corresponding to its aims can be summarized as follows: the majority of Arabic-, Dari- or Somali-speaking refugees in Sweden have limited FHL and/or limited CHL. However, limited FHL and CHL are more common in certain subgroups. The predictors for limited FHL and CHL are not the same. Having a low education level and/or being born in Somalia are associated with inadequate FHL, but not with inadequate CHL. Limited FHL is associated with inadequate CHL. Both refugees' and the healthcare's limited HL were found to affect the participants' experiences of the quality of the communication in HEA. Experiences of poor quality of communication and having benefited little from the HEA are more common among refugees with limited CHL, compared to those with higher CHL. Experiences of communication problems and lack of information related to HEA were found in the qualitative studies as well. In addition, it is more common that those with limited CHL have reported poor general health and impaired psychological well-being, and that they have refrained from seeking healthcare even if they needed help with a health problem.

The distribution of HL

The studies underlying this thesis show that the majority of newly arrived Arabic-, Dari- or Somali-speaking refugees have limited FHL and/or limited CHL. Limited FHL levels among migrants in general have been highlighted previously [85, 88, 91]. Our results were the first publications examining this specific group of refugees. Since then, one more Swedish study [22] has confirmed the high incidence of limited FHL among Arabic- and Dari-speaking refugees. To our knowledge, the studies in this thesis are also the first published articles anywhere presenting CHL levels specifically among refugees.

The prevalence of limited FHL and CHL among newly arrived refugees is notable, as limited HL can lead to negative health behaviours and reduced health [52, 55, 159]. Previous research shows, for example, that those with limited FHL—in comparison with those with higher FHL—have more difficulties interpreting health messages and labels on medicines [64], to a lesser extent follow recommended treatments [64, 72], and participate less in disease preventing efforts [64]. Other research shows that those with limited CHL often have more difficulties communicating with healthcare providers and performing self-care [160].

The proportion of refugees with limited CHL found in this thesis aligns with other research that have examined CHL among migrants arriving from outside Europe or America [85, 87]. However, the study populations in those studies did not only include refugees, and the individuals had on average been in the country longer than those in our studies. Compared to the proportion of people with limited HL in the general populations, the proportion of refugees with limited HL in Sweden seems to be higher [77, 79, 80, 82, 85, 88]. However, as previous studies have neither used exactly the same instruments to measure HL, nor have study populations with the same sociodemographic compositions, and have been carried out in other countries, comparisons must be made with caution.

The results of the studies in this thesis show that it is more common that refugees with a low level of education have limited FHL. Similar results have been found in previous research on general populations, but no previous results have been published on newly arrived refugees specifically. In addition, the results show that it is more common that those born in Somalia have limited FHL, an association that has not previously been examined or published. One explanatory factor for the higher incidence of limited FHL among refugees from Somalia may be that oral information is more common and is often regarded as more important than written information in the Somali culture [161].

The findings implicating that sociodemographic factors can have an impact on an individual's HL align with Sorensen's integrated model of HL, which assumes that societal and environmental factors such as language, culture and societal system can have an impact on individuals' CHL [55].

Differences between FHL and CHL

The result showing different distributions of FHL and CHL levels, i.e., that some refugees have inadequate FHL but at the same time not inadequate CHL, may seem strange. Two potential explanations are that FHL and CHL are two different HL concepts, and that different instruments have been used to estimate them.

FHL was here measured by S-FHL [135], an instrument focusing on one dimension of HL: an individual's ability to read, understand and use written health information [135]. Finding those tasks difficult in a new country with an unfamiliar language, and for some a new alphabet, is understandable. Even if you as an adult refugee have a right by law [162] to be offered courses in Swedish for immigrants, it takes time to fully learn a new language. Many factors influence how long it takes, for example age, level of education from home, health status, and motivation [163]. The study population included in this thesis has only had residence permits for a few years, and a notable proportion have low education and poor health. It is therefore reasonable to assume that a large proportion of those with low FHL also have very limited Swedish language skills.

Further, FHL is not only about reading, understanding and using information in general: it measures skills necessary for managing health information specifically. This particular type of information may contain many words not included in basic courses in Swedish for beginners, words which may also be unfamiliar for native Swedish speakers. In addition, the information may not be targeting refugees specifically, not be culturally sensitive, or not take into account that refugees may have other prior health knowledge than the domestic general population. For refugees arriving from a country or culture with very different views on health or healthcare systems, the gap between their preconceptions and how healthcare works in the new country could be significant [4, 7, 30, 164, 165].

CHL, on the other hand, was measured by HLS EU-Q16, an instrument simultaneously targeting several dimensions of HL [129]. The items in the questionnaire describe situations that do not necessarily require mastering the Swedish language or using written information. For example, it is possible to resolve many of the situations by googling information in your native language, talking to countrymen, or using your own prior knowledge and experiences from home.

Combining results from the studies in this thesis, it is clear that a person could have a CHL level different from their FHL, and that limited FHL and CHL do not share the same predictors. Also, associations with outcomes differ as, e.g., CHL but not FHL matters for refugees' experiences of the HEA. This is important as, first, it shows that FHL and CHL are not exactly the same thing, and should not be used synonymously. Second, it supports previous research showing that it is difficult to guess an individual's HL levels [166, 167].

The difference between FHL and CHL in individuals is also important as it shows that education, often used as a proxy or predictor for limited HL in general, should not be used as a proxy for limited CHL. If it is, people with limited FHL may be treated appropriately based on their FHL level, but not those with limited CHL. This could result in specific needs of the latter not being properly addressed. Removing potential barriers for people with limited HL in general, rather than directing efforts only to those assumed to have limited HL, might therefore be more effective. In addition, it follows the recommendation from the WHO European Review of Social Determinants of Health and the Health Divide [100], stressing the importance of not only working with the most vulnerable in the effort to reduce the social gradient in order to increase equity in health.

Health literacy and the health examination for asylum seekers

The studies in this thesis show that newly arrived Arabic-, Dari- or Somali-speaking refugees with limited CHL are more likely to have experienced poor quality of communication during the HEA, and that they benefited little from the examination. No such differences in experiences exist between refugees with different levels of FHL.

However, results of the qualitative study in this thesis indicate that an individual's FHL is important before and after the HEA, when receiving the invitation letter and the test results. This is also confirmed by a quantitative analysis that was made alongside this thesis, which shows that it is more common that refugees with limited FHL, in comparison with those with sufficient FHL, did not understand what was written in the letter of invitation or were unable to use the information for deciding whether they should participate in the HEA [168]. One explanation as to why FHL and CHL are of different importance in different phases of the HEA might be that written information is used to a varying extent before, during and after the HEA. The results add new knowledge to the field, as HL in the context of the HEA has not been examined in depth before.

An overall interpretation of these results is that participants' FHL and CHL levels are both important for how the HEA is perceived, and that those with the least HL benefit least. This is worrying, as poor health is more common among those with limited FHL and CHL in comparison with those with higher FHL and CHL [77, 78] (Study III). In other words, those with the greatest need to receive health information, new health skills, and help with their health

problems are those who receive the least. This, in turn, means that the HEA can be interpreted as increasing inequity in health instead of increasing equity.

Results gained in this thesis also show that not all organizations providing the HEA meet the needs of their participants. They do not always adapt the information to the individuals' pre-knowledge and language competence, and they do not always help them with their own health concerns or promote their health. An interpretation of this is that not all organizations or staff providing HEA are health literate, i.e., actively help individuals to navigate, understand and use information and services to take care of their own health [169]. This, in turn, exposes inequity in the HEA, as equity in the Swedish healthcare definition requires that care and treatments should be equal and offered to all, regardless of personal characteristics [46]—of which HL could be seen as one. In addition, it highlights problems with the quality of care in the context of the HEA. Not taking the refugees' HL into account conflicts with at least two important quality components: that the healthcare should be patient-centred, and that it should be equitable [113, 114].

That the refugees' individual needs are not met is noteworthy in many ways. Insufficient or incomprehensible information could negatively affect individuals' expectations of what kind of examination, information and help they will receive when participating in the HEA. Findings both from Study III and previous research show that refugees and/or migrants often have too high, or wrong, expectations of the HEA and/or healthcare in general [35, 164, 170]. Poor communication and insufficient information during and after the HEA could lead to unmet expectations as well. For example, misunderstanding the information that only positive results from blood samples will be communicated—that no news is good news—might lead to the perception that results were not reported at all, leaving the participant disappointed.

These findings are worrying as the HEA for many refugees is the first contact with Swedish healthcare [10], and research show that patients' experiences of healthcare could affect future trust [171] and expectations of healthcare [115], healthcare-seeking behaviours [30, 172] and access to healthcare [2, 173]. A possible consequence of this is that the poor quality of communication in the HEA could also increase the risk of inequity in health, as access to healthcare is in itself a social determinant of health, which could be influenced by and influence other social determinants [174]. In addition, the experience of information being insufficient and incomprehensible contributes to the quality-of-care problems in the HEA, as it illustrates ineffective inter-personal care, which is another important component of the quality of healthcare [108].

By giving information that cannot be understood by the participants, the HEA also violates the Swedish Agency for Health and Welfare's regulations about

the HEA [43], as well as the Swedish Patients Act [175], stating that health information should be available and understandable to those it concerns. In addition, when not giving sufficient information, the HEA violates statements in those two documents, saying that the HEA and the healthcare in Sweden in general should be voluntary and based on informed consent [43, 175]. Results both from this thesis and other research show that participants do not always understand that the HEA is voluntary [10, 33, 35].

However, results from this thesis also indicate that some providers are indeed health literate and meet the participants' needs, and that those participants are in turn more satisfied with the HEA. An interpretation of the conflicting results from the qualitative study, which show that the HEA could be experienced both as beneficial and detrimental, is that the quality of care in the HEA varies, as satisfaction is one of many components of quality of care [118, 119]. This is notable as, together with the results showing that refugees with different HL levels do not have the same experiences of the HEA, and do not benefit from it to the same extent, it indicates inequity in the healthcare. A key principle for equity in healthcare is universal coverage, meaning that everyone should have access to the same range of healthcare services corresponding to needs and preferences, regardless of personal sociodemographic characteristics and living conditions, and be empowered to use the healthcare's services [174]. In addition, patients' personal characteristics and abilities should not affect the healthcare [113, 114], and the healthcare should compensate for individuals' inadequate abilities [46]. By violating those principles, the HEA counteracts both the overarching aim of the Swedish Public Health Policy—"to create social conditions that will ensure good health, on equal terms, for the entire population" [102]—and the Swedish Health and Medical Services Act, aiming to give good health and care on equal terms for the entire population [44]. Following Sorensen's integrated model of HL, assuming that HL can affect equity, the finding is reasonable as well.

Another interpretation of the results is that the HEA is an underused resource when it comes to increasing refugees' HL. This is based on the results showing that the refugees, when participating in the HEA, expected and wanted more information about where to go if they have health problems, and how to manage their health in Sweden. By meeting these expectations, refugees' HL might increase. In addition, it could increase refugees' satisfaction with the HEA by limiting the feeling that the HEA does not focus on them as individuals, and promoting the feeling that the HEA cares about them on a personal level. On a higher level, this could help Sweden to better follow the ICESCR's general comment on the Right to Health [98], which states that all human beings have a right to access to health-related information and health education.

Health literacy in relation to seeking healthcare

The result showing that it is more common that newly arrived Arabic-, Dari- or Somali-speaking refugees with limited CHL—in comparison to those with sufficient CHL—have refrained from seeking healthcare is new knowledge. No data linking CHL to healthcare-seeking behaviour has been published before, either for refugees or for people in the general population. Because of the cross-sectional design of the study, it cannot be concluded that limited CHL contributes to having refrained from seeking healthcare; the causation may be in the other direction, or both measurements may have a common underlying cause. However, Sorensen et al.'s integrated model for HL [55] and other theoretical and empirical pathway models [52, 159, 176-178] state that HL through health behaviours can affect health. The findings from the studies in this thesis in no way contradict those theories.

If you have difficulty understanding health information and communicating about health and with the healthcare, which is typical for people with limited HL [57, 179-181], it can be very challenging to use health information and contact healthcare when needed [182]. The way the healthcare system operates, with limited direct personal contacts between providers and patients—often using automatic answering machines—does not make it easier. In addition, those with limited HL often feel shame for their limited abilities and avoid situations that could reveal their lack of competencies [65, 66]. Lack of knowledge about the healthcare system, to which limited CHL could contribute—or be a consequence of [55]—is also a well-known barrier for refugees' and migrants' access to healthcare [2, 4, 30, 183]. In Study IV, this was also one of the most common self-reported reasons for participants' refraining from seeking healthcare.

Another possible pathway linking refugees' CHL levels to their propensity to refrain from seeking healthcare includes the HEA. Limited HL could partly explain negative experiences of the HEA, due to wrong expectations (Studies II and III). According to research, both disappointment and dissatisfaction can lead to an avoidance to seeking health care in the future [4, 30, 164, 172]. In addition, limited CHL during the HEA can also have led to a missed opportunity for receiving knowledge about Swedish healthcare and how to access it. Lack of knowledge about the healthcare system is a well-known barrier for access to healthcare among migrants [5, 30, 184].

Yet another potential reason that refugees with limited CHL are more likely than others to refrain from seeking healthcare is that many of those also have impaired mental well-being. Mental health is taboo, and related to stigma and shame in many of the countries of origin [24, 185-187]. Lack of knowledge about mental health is a known barrier for seeking healthcare among refugees

[187, 188]. Both those things can be seen as being related to the refugees' poor health literacy.

However, according to Sorensen's integrated model [55], and because of the cross-sectional design of the study, there is also theoretical support for an inverse interpretation of the measured association. An alternative interpretation is, therefore, that having refrained from seeking healthcare also means less contact with the healthcare system, and thereby fewer possibilities to receive information and train skills that are important for CHL. Having refrained from seeking healthcare could have hindered the increase of the refugees' CHL and thus contributed to limited CHL.

The results showing that it is more common for refugees with limited CHL to refrain from seeking medical care are important because they are an indication that there are unmet health needs, and that those might be reduced by taking the refugees' HL into account. Visiting the healthcare early when a problem arises is typically preferable to waiting until the condition becomes serious, both for the individual's own well-being and for society, as early treatment is often easier, cheaper and requires less healthcare resources. On the other hand, overuse of healthcare because of minor problems that could be helped by self-management is not good either.

In addition, the result is important as it shows that those with lower CHL, who often also have the poorest health [72, 77-81], (study III), might not even come in contact with or use the healthcare system. This is worrying, as it contributes to inequity in healthcare and to problems with the quality of care. Inequity is affected, because the findings indicate that the key principle of universal coverage [174] is violated, as limited HL—which is a personal characteristic—might prevent people from seeking healthcare. The principle of “*equal access for equal needs*”, included in several definitions for equity in healthcare [103, 104, 106, 107], might be violated by this as well. However, due to the lack of knowledge of which kind of healthcare the participating refugees needed, no conclusion regarding this can be drawn. The quality of the healthcare is affected, because access is a fundamental component of quality of care [108]. If healthcare cannot be reached, other quality components, for example, those stating that healthcare should be efficient and effective [108, 113-115], are irrelevant. Additional research is needed to study more why the refugees refrained from seeking healthcare.

To decrease the number of refugees refraining from seeking healthcare even if there is a health problem, it might be useful to offer all newly arrived refugees information about the healthcare system as soon as possible after their arrival in Sweden. The information could explain how the healthcare works,

and what kind of health problems they can help with and at what cost. However, the information must be tailored specifically to the refugees it is intended to reach, so that it is understood and perceived as important to those who are to receive it.

Health literacy in relation to health

Poor general health among individuals with limited CHL has been reported among people in general before [77, 78], but not among refugees. That limited CHL is also associated with impaired psychological well-being is new knowledge. Considering the meaning of having limited CHL, i.e., having difficulties accessing, understanding, appraising and applying health information [55], a reasonable interpretation of these results is that limited CHL likely contributes to refugees' poor health. This interpretation is also consistent with the assumption, mentioned in the previous section, that HL can affect health through health behaviour, which is part of Sorensen's et al. integrated model of HL [55] as well as other models of theoretical and empirical pathways [52, 159, 176-178].

The results showing that individuals with insufficient CHL receive less health-promoting information and help from the HEA support this interpretation, as does indirectly the finding that not seeking healthcare when it is needed is associated with insufficient CHL: not seeking healthcare results in less knowledge about how to maintain and improve health in Sweden.

According to Sorensen's integrated model of HL [55], poor health, however, can also contribute to the low CHL among refugees. Poor health can prevent refugees from taking part in the establishment programme, learning Swedish or participating in internships [31, 163]. This in turn may affect refugees' ability to find, understand, apply and appraise information needed for maintaining and improving health, which in turn could affect the refugees' health. In other words, health can both affect and be affected by HL. To summarize, my overall interpretation of the results is that they indicate that part of the poor health among refugees is unnecessary, and that it could be improved if refugees' HL levels are properly considered.

Methodological considerations

All studies have strengths and weaknesses that should be taken into consideration when interpreting the results. Strengths and weaknesses for the quantitative studies (Studies I, II and IV) and the qualitative study (Study III) are presented in different sections as concepts used when talking about quality in quantitative and qualitative research differ. By presenting the strengths and weaknesses that I think are most important, I also hope to be able to help others who plan similar research.

Validity and reliability of the quantitative studies

In quantitative research, the concepts of validity and reliability are often used to judge the quality of the work [189]. Validity refers to how well the instrument measures what it is intended to measure. External validity, also called generalizability, refers to how well the results apply to other groups than the study population. Reliability refers to how precise the instrument is: the instrument's ability to give the same answer at different points in time, under otherwise identical conditions.

The quantitative studies in this thesis share many strengths and weaknesses, as they are based on data from questionnaires with similar or identical questions and collected from similar study populations. One notable strength in three studies is that the strategic sampling, recruitment process, translation of the questionnaire and use of language supporters facilitate participation among people in the target group. Refugees having another native language than the majority of the population or who are illiterate are otherwise often excluded from studies. However, the use of language supporters may also have influenced the answers of participants who completed the questionnaire orally.

The translation of questionnaires into different languages was challenging and required huge efforts. The use of qualified translators did not guarantee appropriate translations for the study populations in focus. Common failures included use of inappropriate words, dialects, or a language that was too academic. This happened even if the translators were instructed to use as plain language as possible—language suitable for people with only elementary schooling—and to prioritize keeping the idiomatic and conceptual meaning of the sentences over translating word by word, as recommended for cross-cultural adaptations of an instrument [132] and material for people with limited HL [190].

Back-translations and feedback on the questionnaires from key people from the study populations—such as language supporter and/or cultural mediators

working in the civic orientation—were essential for the quality of the final versions. This was especially true for the Somali translations, as the Somali language became an official written language as late as 1972 [191] and still shows a great deal of variation between dialects and regions. Several Somali-speaking language supporters from different regions in Somalia were consulted to go through the first version of the translated questionnaire together, checking the match with the Swedish version and whether it was understandable. This worked well as they could together come up with alternative formulations expected to be understood by most people speaking the language, regardless of dialect. The feedback on the Somali language in the questionnaires, when used in practice, has generally been positive.

It may be seen as a weakness that several subjective measures were used, which could be interpreted differently depending on cultural and educational background [5, 7, 192] and because of different views on health and healthcare [7, 171]. The question used to measure “Having refrained from seeking health care” in Study IV is, from my point of view, perhaps the question that suffers most from this weakness. First, it is really two questions in one: asking both whether the participant has had any health problems *and* whether the participant has refrained from seeking healthcare. Second, both parts of the questions are subject to interpretation: It is not specified what should be considered a health problem—how severe it has to be—or what kind of healthcare service that was not sought for. This means that two people with the same health problem could give different answers to the question. For, example, if one person thinks that the health problem is caused by biological factors—and should be treated by the healthcare--and another person think the health problem is caused by some supernatural power—and that it could be helped by family members, then the former might answer *yes* and the latter *no*.

The purpose of the question was not to get a full picture of what kind of health problems refugees have, how serious they are, or what kind of healthcare service they are missing. In my study, the intention was to measure how common unspecified self-perceived unmet healthcare needs are among refugees, allowing me to analyse whether they are more common among those with limited HL, compared with those with sufficient HL. Considering the purpose of the question and that it has been used as an indicator for unmet healthcare needs in other studies [151, 155], my conclusion is that it was reasonable to use it in this study.

However, most of the key variables were measured by more commonly used questions or instruments that have been proven valid in many different study populations [25, 129, 149, 193]. Furthermore, good face validity was reported for the new questions that were used about the HEA, when evaluated in the pre-testing of the translated questionnaires that was performed before the real

data collection. In addition, Cronbach's alpha was calculated for the multiple-item variables "*quality of communication*" and "*receiving healthcare information*" in Study II and indicated that the internal consistency was satisfactory. Regardless, it must be considered that the refugees may still have reported better experiences of the HEA than they actually had, because in many cultures it is impolite to question authorities [2]. In other words, real experiences of the HEA might be worse than the results show.

The use of HLS EU-Q16 for measuring CHL among newly-arrived refugees also turned out to be suboptimal for the present study population. This was not apparent until the real data collection. The problem was that not all participants had during their time in Sweden experienced all situations described in the different items in HLS EU-Q16. In Studies I and II, this possible scenario was taken into consideration beforehand by adding the response alternative "don't know" (to be interpreted as a missing response) to the original four. Unfortunately, this caused many missing CHL values, and different methods had to be used in the studies to tackle this problem.

As a reaction to the many missing values of CHL in Studies I and II, the response alternative "don't know" was excluded in Study IV. In this way the HLS-EU-Q16 version used in this study was more similar to the original version [136], to which the respondent answers verbally, and "don't know" is only ticked by the interviewer when the respondent does not give any of the other four response alternatives. Compared to having the response alternative "don't know" included as in Studies I and II, the participants did not appear to have more questions about the items, or problems with how to answer, during the data collection for Study IV. Neither did the proportions of refugees with different levels of CHL differ remarkably between the studies.

During the data collections, participants were also asking what kind of health information the items in the S-FHL scale and in the HLS EU-Q16 refer to. In addition, they stressed that they could answer differently depending on whether the situation that was asked about in the instruments took place in Sweden or in their country of origin, and whether the health information was given in Swedish or their native language.

The refugees' feedback is important and supports theories describing HL as a dynamic concept [57] and something that could be reduced when coming to a new and unfamiliar context [95]. When HL is measured among newly arrived refugees in the future, it is important to be aware that they "live in two contexts" and can interpret items differently depending on their pre-knowledge and previous experiences in their home country and culture, which may differ from their new country [132]. One suggestion for improvement is to specify

which kind of information the items refers to, in order to develop a more precise instrument.

Another concern regarding the assessments of HL is that, considering what it means to have limited FHL, those with limited FHL might have had more trouble filling in the questionnaires. However, the use of language supporters on site made it easier for them to respond and reduced the risk that unintended answers were filled in. On the other hand, the participants, because of the presence of the language supporters, might have exaggerated their HL skills to avoid the shame of admitting to limited HL [65, 133]. In other words, the proportion of refugees with inadequate or problematic HL may be underestimated in the results.

The cross-sectional design of Studies I, II and IV do not allow causality inference. Whether CHL causes the negative health outcomes found in the studies—or whether it is the other way around—could therefore not be determined. However, considering what it means to have limited CHL, as well as previous HL research and pathways models for HL [52, 55, 159], it is likely that CHL at least partly influences the negative health outcomes. In addition, it is more likely that the independent variables used in Study I influence FHL and CHL, rather than the other way around. For example, personal traits such as sex and age are truly independent, and with certainty not influenced by HL levels, but the statistical results of the study might still suffer from some sampling bias in that direction. For example, it is hypothetically possible that different HL levels may causally affect the likelihood that people with different independent traits completed the questionnaire.

Note also that the results of the quantitative studies cannot be generalized to all refugees. First, the study populations do not include all refugee groups. Second, generalizations of HL results outside Sweden in other countries are not optimal, as HL is highly related to the context [55, 59], and organizations' HL may differ between countries. However, with that being said, the findings or parts of them could still also be valid for others sharing characteristics and experiences with the refugees in my studies, but for whom exactly is impossible to say.

The qualitative study

In qualitative research, the concepts of *credibility*, *dependability*, *confirmability* and *transferability* are often used to judge the trustworthiness of the results [157, 194]. Credibility refers to how well the findings describe reality. Dependability refers to the extent to which the results would be the same if the study was repeated. Confirmability refers to the extent the findings are based on the participants' narratives and words rather than on potential researcher biases. Transferability refers to the extent the findings may be true for people in other settings.

Credibility was sought by recruiting participants with different sociodemographic characteristics, who had recently participated in the HEA in different places in Sweden. The fact that the participants had experiences from many different places and had different demographic, migratory and health-related characteristics contributed to a variation of experiences of the HEA.

As a measure to increase *credibility*, the focus groups were held in the participants' own languages. The use of moderators speaking the participants' native language meant that the discussion could run more freely and was not interrupted continuously, which is the case when an interpreter is used [144]. Using this method, the participants got more time to talk themselves, which probably gave richer data. That the moderator shared the culture with the participants also meant that they could more easily understand the essence of what the participant talked about, and ask more appropriate probing questions [141].

Another strength in using moderators from the same culture as the participants was that it weakened the power relationship that clearly exists when the moderator is an "outsider"[143]. In an effort to mitigate other power relationships that could hinder participants from fully expressing themselves, participants were also divided on the basis of sex and education level. The use of only female moderators served the same purpose. However, even if women, according to key informants for the study population, ought to work well for both male and female groups, they might have hindered the men from fully expressing themselves.

However, the use of moderators speaking another language was also limiting, as it prevented the researcher from being directly involved in the data collection and introducing probing questions relevant to the aim of the study on site. Furthermore, the author could not access all data before the audio files had been transcribed and translated. Translations, in turn, may have been affected by the persons transcribing and translating the data also adding their interpretation of it. However, being aware of potential interpreter bias [141], uniform

guides for translation and transcription were used. In addition, 10% of each transcript was checked by a third bilingual person and the moderators were asked to give feedback on the final results.

In future similar studies, it may be useful to keep using moderators that speak the participants' native language but also to have an interpreter present who can translate for the observing researcher everything that is said during the discussion. In that way, the discussion could run rather freely, while giving the researcher an opportunity to add some probing questions if needed. Furthermore, it would mean that the researcher will not only get access to the data in the form of translated transcripts after data collection is completed.

In the analysis of the data collected, credibility was improved by their analysis by two different researchers, first independently and then together. Furthermore, we frequently went back and forth between suggested categories and the raw data to secure that no relevant data were missed or had been misinterpreted. Descriptions were also presented of who we are and of our backgrounds. Further, extensive quotations were given for each subcategory in order to allow the reader to judge the appropriateness of the categorizations created. Finally, two of the moderators read the results to confirm that they were in line with their experiences of what was discussed during the focus groups. Both agreed with the condensed and categorized result, and thought that the participants' experiences were well captured.

Confirmability was sought by carefully describing the audit trail and by the researchers taking into account that their background and prerequisites could affect the results. *Dependability* was sought by systematic work in all phases of the execution of the study. All moderators were, for example, given information about focus group methodology, ethics, and the purpose and the background of the study. In addition, a similar question guide was used by all moderators, and the transcript protocol by Mc Lellan [147] was used by those transcribing the audio files.

A dialogue was also held between me and one of the other co-authors (LM) regarding the similarities and differences of the content over time. This became a concern as data were collected over a period of one and a half years. In order to facilitate *transferability*, sociodemographic characteristics for the participants have been published, as has been the context in which they were recruited and where the focus group discussions took place.

Suggestions for the future

In healthcare

Negative health consequences not only depend on individuals' limited HL but also on demands and complexities in the society in which the individual resides [195]. If the healthcare system is complicated and gives little and/or difficult information, more individual advanced HL abilities are needed to be able to understand and use it properly. By being a health literate healthcare organization, it is suggested that the healthcare system could compensate for the individual's limited HL [196], be more responsive to individual needs and improve health outcomes [197]. One method for making healthcare organizations more health literate is to make more healthcare professionals aware of the HL concept, increase their understanding of the consequences of limited HL, and make them more sensitive to various HL needs [169, 198, 199]. Good training in HL for health professionals has proven to lead to better communication, adherence to treatment [3] and quality in healthcare [200-203].

Some methods commonly recommended in the HL field for improving the quality of communication between patients and providers are clear communication [181, 204-206], questions eliciting the patients' explanatory model for health [207, 208] and using teach-back, which invites the patient to retell what has been discussed during the visit [39, 181, 198, 204, 208]. A Swedish version of teach-back exists, called "förstå mig rätt" [209]. To facilitate patients asking questions [199, 204, 206, 208], the use of open questions [165, 204] and patient/client-centred communication [120, 210, 211] is also recommended. Other recommendations for improved communication between providers and migrants specifically are cultural sensitiveness/competency/humility [7, 18, 37, 39, 94, 165, 211, 212], using pictograms and other visual materials as well as audio and video [39, 213], and using qualified interpreters and cultural mediators [18, 39, 199].

Cultural mediators are usually people from the same culture and/or country as the refugees, but who have lived in the host country longer and who also understand its culture, norms and structures. Thanks to this, they can give information and discuss and answer questions in the refugees' native language. They can also sustain a dialogue about the information, comparing situations and procedures in the old and the new country [39], and teach people how to learn about health [214]. The main difference between interpreters and cultural mediators is that the role of interpreter is strictly to directly translate speech, while the cultural mediator can translate less strictly and also help bridge cultural differences [18, 215].

Efforts are needed to improve the amount of usable and meaningful information prior to, during and after the HEA. This is also true for information in the native languages. One way of meeting those needs is by improving the quality of the written information, for example, the content and the language used in the invitation letter. Examples of important points to include in such letters, according to the findings in this thesis (Study III) and other literature [210, 216], are the purpose of the test/examination, what it will include, how it will be performed, and how to receive and interpret the test results. Another way is by giving information the participants need and themselves want, in order to be able to prevent ill health and manage their health in the new country. Information that refugees may want includes, for example, how to get into contact with healthcare, and information about the most common and specific health problems/diseases in the host country (Study III).

By answering to the need of usable and meaningful information, it is possible that future participants become more satisfied with HEA. In addition, it may increase the refugees' CHL and enable them to be more active in decisions regarding their own health. However, the use of interpreters and translated material is challenging and does not always facilitate communication or increase understanding [2, 4, 10, 35, 217] (Study III). Care must therefore always be taken to choose interpreters and translators with good skills to secure the quality of the communication (Study III).

Another potential improvement lies in ensuring that individual health needs are better met, and psychological support, if needed, is made available within what the participants think is a reasonable time frame, something that participants in an HEA miss [33, 35] (Studies II and III). What a reasonable time frame is for receiving support or help with health problems is open to discussion, and depends on your background. Many refugees are used to a healthcare system that provides access to a doctor or medical treatment more promptly than in Sweden [218] (Study III). Regardless of the reasons for not receiving immediate help, it is important to inform when help could be expected and about why health needs cannot be handled directly, or at all. A lack of answers can be frustrating and lead to patients worrying unnecessarily. In addition, it violates the patients' rights to information in the Swedish Patient Act, which states that patients have the right to be informed about the time at which he or she may expect to receive care [175].

Because it can be difficult to know who has limited HL [72, 219], and clarity between patients and healthcare professionals is beneficial in general, regardless of the HL level [39, 220], it might be better to use strategies to improve the quality of communication for all, rather than limiting them only to people suspected of having limited HL.

Outside healthcare

In order to improve individual HL, and remove barriers for people with limited HL in general, several actors in society need to be health literate, not only the healthcare sector [39]. To accomplish this for migrants specifically, the use of cultural mediators is once again recommended [39]. Cultural mediators can lead group dialogues about health in the community, facilitating collaborative learning and social support, both of which are factors that could improve HL—critical HL, specifically [221]. Some studies, both from Sweden and other countries, indicate that the use of cultural mediators in combination with dialogue-based communication may increase migrants' HL [165, 222, 223].

In Sweden, cultural mediators are also used in the civic orientation [224]. In this course, which, under the Swedish Establishment Act [225], should be offered to all refugees between the ages of 18 and 65, refugees are given 60 hours of education about the Swedish society. Four of the sixty hours focus on how the Swedish healthcare system works and is organized. However, in many regions, too little time is set aside in the civic orientation course to talk about health. By increasing the time spent on health issues and increasing refugees' own HL skills in this already established programme, more refugees may be able to find help with their health when they need it.

Successful implementations of extended civic orientation in some regions—including more hours of health communication than the ordinary civic orientation—shows that this is possible [224, 226, 227]. Information about the HEA in the civic orientation would be of value both for those participating in the civic orientation and for other migrants, as participants in the civic orientation often share information they have received there with others [226]. That way, the information can also reach newly arrived refugees who often turn to countrymen that have been in the new country longer for information and help with health problems [187](Study III).

Further studies

The following research is needed:

- Prospective studies following refugees over time to examine whether limited FHL and/or CHL leads to negative health outcomes.
- Studies examining mechanisms of how HL influences different health outcomes.
- Development of HL instruments targeting newly arrived refugees specifically.
- Validation of existing HL instruments when used among newly arrived refugees.

Studies are also desirable as to how health literate different health care organizations and healthcare providers are, examining also to what extent it matters for refugees' experiences of healthcare, as well as its outcomes. In addition, it would be of value to investigate efforts that could be effective for improving refugees' HL, as well as efforts that could help refugees with limited HL manage their health outside of healthcare.

Conclusions

This thesis adds new important knowledge to the field of HL, migration and health. The studies help to fill the gap of knowledge about the distribution of HL levels among refugees, and about how important HL is for refugees' experiences of HEA, health-seeking behaviour and health.

- The findings show that many newly arrived refugees in Sweden, speaking Arabic, Dari or Somali, have limited HL. This is important to take into consideration as limited HL is also related to poorer experiences of the HEA, to refraining from seeking healthcare despite having health problems, and to poor health in general, findings that also are demonstrated in this thesis.
- The findings show that inadequate HL is more common in certain subgroups. Furthermore, FHL and CHL do not share the same predictors and are not of equal importance for the experiences of HEA. This is important, as it shows that FHL and CHL are not exactly the same concept and can be of different importance in different contexts. It also shows that education level, often used to estimate individuals' HL in general, is not an appropriate proxy for CHL.
- The findings show that a considerable number of refugees have negative experiences of the HEA and that those experiences are related to limited individual and organizational HL. Dissatisfaction with healthcare can lead to distrust and low expectations of healthcare, and perhaps also to inadequate healthcare-seeking behaviour and inappropriate underuse of the healthcare system.

At the present state, HL is still an unknown concept to many people working in healthcare. Spreading the new knowledge reported in this thesis, that many newly arrived refugees have limited HL, and that HL can be important for refugees' experiences of HEA, health-seeking behaviour and health, might lead to a better response to refugees' needs. By taking HL into consideration in the communication about and within the HEA, future negative experiences of it might be reduced, as may also refugees' mistrust in Swedish healthcare. In addition, unmotivated differences in healthcare might be reduced, and equity in the healthcare system, as well as in health, may increase.

Sammanfattning (Summary in Swedish)

Denna avhandling undersöker hälsolitteracitet hos nyanlända flyktingar. Hälsolitteracitet handlar om en individs kunskap, motivation och förmåga att få tag på, förstå och använda hälsoinformation i olika sammanhang för att främja och bibehålla hälsan. De nyanlända flyktingar som ingår i avhandlingens studier är personer som fått uppehållstillstånd av eget asylskäl eller på grund av att de har en relation med någon som fått uppehållstillstånd av asylskäl (så kallad familjeanknytning). Arabisk-, dari²- och somalisktalande nyanlända flyktingar valdes utifrån att de var de största flyktinggrupperna i Sverige när arbetet med avhandlingen påbörjades.

Avhandlingens övergripande syfte var att undersöka hur olika typer av hälsolitteracitet (funktionell respektive komplex) ser ut hos arabisk-, dari- och somalisktalande nyanlända flyktingar i Sverige. Ytterligare syften var att undersöka i vilken utsträckning olika sociodemografiska faktorer är associerade med inadekvat hälsolitteracitet. Ett annat syfte var att undersöka om hälsolitteracitetsnivåerna har ett samband med hur flyktingar skattar sin egen hälsa, hur de upplever hälsoundersökningen för asylsökande och i vilken utsträckning de söker vård.

Tre kvantitativa tvärsnittsstudier genomfördes. Data samlades in via två olika enkätundersökningar, som riktade sig till arabisk-, dari- och somalisktalande nyanlända flyktingar som deltog i kurser för svenska för invandrare eller i samhällsorientering. Därutöver genomfördes en kvalitativ studie, inom vilken data samlades in genom fokusgruppsdiskussioner med arabisk- och somalisktalande nyanlända flyktingar som deltagit i hälsoundersökningen för asylsökande. All data samlades in under perioden 2013–2016. Kvantitativa data analyserades genom olika statistiska metoder, främst med hjälp av deskriptiv statistik och univariata- och multivariata binära logistiska regressionsanalyser. Kvalitativa data analyserades med hjälp av Graneheim och Lundmans metod för kvalitativ latent innehållsanalys.

Huvudresultaten visar att majoriteten av alla nyanlända arabisk-, dari- och somalisktalande flyktingar i Sverige har begränsad funktionell- och/eller komplex hälsolitteracitet. Vidare visar resultaten att låg utbildningsnivå och/eller

² Dialekt av persiskt språk som talas i Afghanistan.

att vara född i Somalia har ett samband med att ha inadekvat funktionell hälsolitteracitet, men inte med att ha inadekvat komplex hälsolitteracitet. Inadekvat komplex hälsolitteracitet uppvisade endast ett samband med begränsad funktionell hälsolitteracitet.

Det var vanligare att de med begränsad komplex hälsolitteracitet uppgav att de upplevt dålig kvalitet på kommunikationen och att de fått lite nytta av hälsoundersökningen för asylsökande. Resultaten i den kvalitativa studien bekräftade att deltagarna upplevde kommunikationsproblem och brist på information i samband med hälsoundersökningen för asylsökande. Vidare var det vanligare att de med begränsad hälsolitteracitet rapporterade låg självskattad generell hälsa, försämrat psykiskt välmående och att de hade avstått från att söka vård trots att de varit i behov av det.

Sammanfattningsvis visar resultaten att begränsad hälsolitteracitet är vanligt bland nyanlända flyktingar i Sverige och att hälsolitteracitet tycks vara av betydelse för flyktingars upplevelser av hälsoundersökningen för asylsökande, vårdökande beteende och hälsa. Hälsolitteracitet behöver tas i beaktande vid arbete med flyktingar för att hälso- och sjukvården, och samhället i stort, ska leva upp till de mål som finns om en god och jämlik hälsa.

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