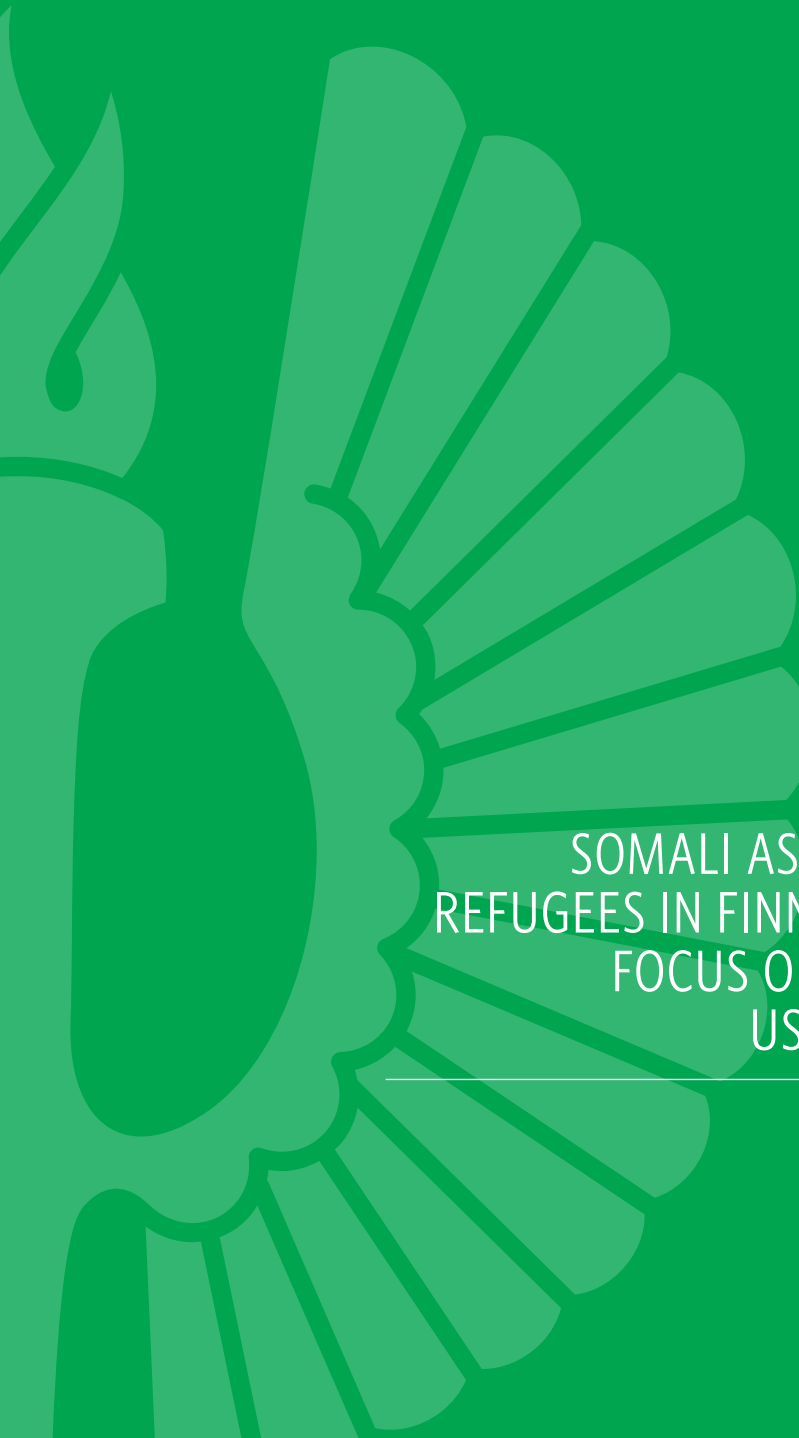




Turun yliopisto
University of Turku



SOMALI ASYLUM SEEKERS AND REFUGEES IN FINNISH HEALTH CARE – FOCUS ON PRIVACY AND THE USE OF INTERPRETERS

Niina Eklöf



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Niina Eklöf

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FOCUS ON PRIVACY AND THE USE OF INTERPRETERS**

University of Turku, Faculty of Medicine, Nursing Science, Finland

Annales Universitatis Turkuensis, Painosalama Oy, Turku 2018

ABSTRACT

Privacy is one of the key principals in nursing ethics. It is culturally dependent, and everyone defines it based on their own culture. Respect for privacy is considered to be important in health care, which requires health care professionals' understanding of privacy in different cultures. The aim of this study was to describe the content, importance and realisation of privacy for Somali asylum seekers and refugees, and the factors related to the use of interpreters in Finnish health care, and to identify the factors related to the use of interpreters in health research.

The study was conducted in four sub-studies. The data were collected by 1. focus group interviews from Somali asylum seekers (n=18), 2. by a questionnaire from Somali refugees (n=29), 3, by interviewing nurses (n=8). In the fourth sub-study a literature review was conducted. Data were analysed by content analysis.

According to the results, the content of privacy can be divided into visual, physical and informational privacy. The importance of privacy is related to respect of religion, culture and community, feeling of freedom. It is a way for individuals to have the respect of their family and community. The loss of privacy is related to feelings of shame, which is also targeted at the family and community. The realisation of privacy is related to the patient, health care professional and interpreters. Privacy is realised when the patient can make his/her own decisions, is able to act according to Somali culture, gets the appointment with health care quickly and understands his/her treatment. Personal and professional factors of the healthcare professional, such as kindness, ability to focus on health and knowledge about Somali culture, were related to the realisation of privacy. The presence of interpreter weakened the realisation of privacy; however, the personal and professional characteristics of the interpreter improved the realisation. The factors related to the use of interpreters in health care were related to the patient, health care and interpreter. The factors related to the patient included patients' perceptions and desires concerning the interpreter. Factors related to health care included planning and realisation of the appointment. The factors related to the interpreter included the knowledge, role and personal characteristics of the interpreter. Factors related to the use of interpreters in health research were related into planning and conducting research.

As a conclusion, in Somali culture, privacy is strongly connected with religion and the community and it is a collective phenomenon. The realisation of privacy in health care requires a common understanding of the Somali culture and the treatment. The use of interpreter in health care requires careful planning and realisation.

Keywords: Privacy, Nursing ethics, Somali, Asylum seeker, Refugee, Interpreter, Health research

Niina Eklöf

SOMALIALAISET TURVAPAIKANHAKIJAT JA PAKOLAISET SUOMALAISESSA TERVEYDENHUOLLOSSA – YMMÄRRYS YKSITYISYYDESTÄ JA TULKIN KÄYTÖSTÄ

Turun yliopisto, Lääketieteellinen tiedekunta, Hoitotiede, Suomi

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TIIVISTELMÄ

Yksityisyys on yksi hoitotyön eettisistä periaatteista. Se on kulttuurisidonnainen käsite, joka määritellään oman kulttuurin kautta. Yksityisyyden kunnioitus edellyttää terveydenhuollon ammattilaisilta ymmärrystä yksityisyydestä eri kulttuureissa. Tämän tutkimuksen tarkoituksena oli kuvata somalialaisten turvapaikanhakijoiden ja pakolaisten yksityisyyden sisältö, tärkeys ja toteutuminen suomalaisessa terveydenhuollossa sekä tulkin käyttöön liittyviä tekijöitä terveydenhuollossa ja terveyteen liittyvässä tutkimuksessa.

Tutkimus toteutettiin neljässä osatutkimuksessa. Aineistot kerättiin 1. somalialaisilta turvapaikanhakijoilta (n=18) focus group –haastatteluilla, 2. somalialaisilta pakolaisilta (n=29) laadullisella kyselylomakkeella ja 3. haastatteleamalla terveydenhoitajia (n=8). Neljäs osatutkimus toteutettiin kirjallisuuskatsauksena. Aineistot analysoitiin sisällön analyysillä.

Tulosten perusteella yksityisyys somalikulttuurissa on sisällöllisesti visuaalista, fyysistä ja tiedollista. Yksityisyyden tärkeys on uskonnon, kulttuurin sekä perheen ja yhteisön molemminpuolista kunnioitusta, vapauden tunnetta sekä mahdollista häpeää yksityisyyden menettämisestä perheessä ja yhteisössä. Yksityisyyden toteutumiseen liittyvät potilas, terveydenhuoltohenkilöstö ja tulkki. Yksityisyyden koettiin toteutuvan, kun potilas sai itse päättää asioistaan, pystyi toimimaan oman kulttuurinsa mukaisesti, sai ajan vastaanotolle nopeasti ja ymmärsi hoitoonsa liittyvät asiat. Terveydenhuoltohenkilöstön persoonalliset ja ammatilliset tekijät, kyky keskittyä terveysasioihin ja somalikulttuurin tuntemus lisäsivät yksityisyyden toteutumista. Tulkin läsnäolon koettiin heikentävän yksityisyyttä, mutta tulkin henkilökohtaiset tekijät sekä ammatillinen osaaminen liitettiin yksityisyyden hyvään toteutumiseen. Tulkin käyttöön liittyvät tekijät terveydenhuollossa liittyvät potilaaseen, terveydenhuollon henkilöstöön ja tulkkiin. Potilaaseen liittyvät tekijät sisälsivät potilaiden toiveet ja näkemykset tulkkiin liittyen. Hoitohenkilökuntaan liittyvät tekijät sisälsivät potilaan vastaanoton suunnitteluun ja toteutukseen liittyviä tekijöitä. Tulkkiin liittyvät tekijät sisälsivät tulkin tiedot, roolin ja henkilökohtaiset tekijät. Tulkin käyttöön liittyvät tekijät terveyteen liittyvässä tutkimuksessa jakautuivat tutkimuksen suunnitteluun ja tutkimuksen toteutukseen.

Johtopäätöksenä voidaan todeta, että somalikulttuurissa yksityisyys on vahvasti uskontoon ja yhteisöön sidoksissa oleva kollektiivinen ilmiö. Yksityisyyden toteutuminen terveydenhuollossa edellyttää hoitohenkilökunnan ja potilaan yhteistä ymmärrystä somalikulttuurista ja hoidosta. Tulkin käyttö terveydenhuollossa ja tutkimuksessa edellyttää hyvää suunnittelua ja toteutusta.

Asiasanat: Yksityisyys, Hoitotyön etiikka, Somali, Turvapaikanhakija, Pakolainen, Tulkki, Terveystieteellinen tutkimus

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LIST OF ABBREVIATIONS

| | |
|---------|--|
| AIDA | Asylum Information Database |
| CINAHL | Cumulative Index to Nursing and Allied Health Literature |
| ETENE | The National Advisory Board on Social Welfare and Health Care Ethics |
| ICN | International Council of Nurses |
| MEDLINE | National Library of Medicine |
| RSMI | Remote simultaneous medical interpreter |
| TENK | Finnish Advisory Board on Research Integrity |
| THL | National Institute for Health and Welfare |
| UN | United Nations |
| UNESCO | United Nations Educational, Scientific and Cultural Organization |
| UNHCR | United Nations Refugee Agency |
| WHO | World Health Organization |
| WMA | World Medical Association |

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LIST OF ORIGINAL PUBLICATIONS

This thesis is based on the following publications, which are referred to in the text with Roman numerals I – IV.

- I. Eklöf N, Abdulkarim H, Hupli M & Leino-Kilpi H. 2016. Somali asylum seekers' perceptions of privacy in health care. *Nursing Ethics* 23(5), 535-546.
- II. Eklöf N, Hupli M & Leino-Kilpi H. 2017. Realisation of privacy for Somali refugees in health care – factors related to the patient, health care professional and interpreter. Submitted.
- III. Eklöf N, Hupli M & Leino-Kilpi H. 2015. Nurses' perceptions of working with immigrant patients and interpreters in Finland. *Public Health Nursing* 32(2), 143-150.
- IV. Eklöf N, Hupli M & Leino-Kilpi H. 2017. Planning focus group interviews with asylum seekers – factors related to the researcher, interpreter and asylum seekers. *Nursing Inquiry* 24(4), Epub ahead of print. [[L]]
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The original publications have been reproduced with the kind permission of the copyright holders. The summary also contains unpublished material.

1 INTRODUCTION

The Universal Declaration of Human Rights (United Nations [UN] 1948) states that “no one shall be subjected to arbitrary interference with his privacy” (Article 12), and “everyone has the right to seek and to enjoy in other countries asylum from persecution” (Article 14). Privacy is considered as a human right (UN 1948) and according to several laws and declarations, people and patients have the right to respect for privacy (World Health Organization [WHO] 1994, Act on the status and rights of patients 785/1992). Privacy is also considered to be one of the key elements of nursing ethics (Beauchamp & Childress 2009), and is observed in many ethical codes for nurses both nationally (e.g. Finnish Nursing Association 2016) and internationally (e.g. International Council of Nurses [ICN] 2012).

The world’s refugee population has increased during the last few years. In 2014, almost 60 million people had to flee due to political or other conflicts. This is 8.3 million more than in 2013 (United Nations Refugee Agency. [UNHCR] 2015.) In 2016, the number had increased to 65.5 million. According to the statistics of UNHCR (2017a), the majority of refugees (40.3 million) are located internally, a total of 22.5 million people are located outside their own country as refugees, and 2.8 million as asylum seekers. In Europe, in 2016 more than 1.2 million first-time asylum seeker applications for international protection were received in EU countries (Eurostat 2017).

The position of asylum seekers and refugees is connected with unique and complex health care needs, which has been recognised to require attention upon arrival in the host country and throughout the process of settlement (Grove & Zwi 2006). Asylum seekers have been reported to suffer from many physical and mental health problems, and they utilise health services at a higher rate than the host population (Hadgkiss & Renzaho 2014).

Working in health care with asylum seekers requires several specific competences. Besides general cultural competence, health care professionals should have knowledge of the political situation in the country of origin, knowledge about the common diseases in the country of origin, knowledge of the health effects of refugees’ pre- and post-settlement experiences, awareness of the juridical issues in the host country, ability to deal with asylum seekers’ traumatic experiences and skills to explain the health care system of the host country (Suurmond et al. 2010). Working in health care with asylum seekers and refugees is challenging for health care professionals, and there is a need for specific

guidelines, professional support and availability of relevant up-to date information about the current asylum seeker and refugee situations. Health care professionals should ensure adequate time during the appointment for building trust, communication and cultural understanding. (Robertshaw et al. 2017.) It is recommended that specific clinical guidelines should be developed for health care with asylum seekers and refugees.

Interpreters are usually used to decrease the language barriers in health care, especially with new immigrants. The use of trained professional interpreters affects positively on patients' satisfaction, quality of care and outcomes (e.g. Flores 2005, Karliner et al. 2007) but it is also reported to be a major barrier to health care for immigrant patients (Hadgkiss & Renzaho 2014). However, the use of interpreters changes the dual relationship between the patient and health care professional into a relationship between the patient, health care professional and interpreter, causing changes in trust issues, roles and practical issues for the three parties involved in the relationship (Miller et al. 2005).

Research with human beings in the position of asylum seekers requires special attention to methodological and ethical issues. Pre- and post-settlement experiences set asylum seekers in a vulnerable situation, which has raised discussion on the ethics of conducting research with asylum seekers (Leaning 2001, Rousseau & Kirmayer 2010, Zion et al. 2010). Special attention to research ethics with asylum seekers, refugees and immigrants is given in the guidance note by the European Commission Directorate-general for Research and Innovation (2017). According to WHO's Standards and Operational Guidance for Ethics Review of Health-Related Research with Human Participants, researchers should be sensitive and respect the communities' cultural, traditional and religious practices (WHO 2016). This requires better recognition of the cultural aspects of research methodology, which are usually based on Western traditions (Carey 2016). In studies, asylum seekers and refugees are usually studied together, lacking special attention on the particular needs of asylum seekers.

This study is in the field of nursing ethics. The aim was twofold. First, in the empirical part, the aim was to describe the content, importance and realisation of privacy of Somali asylum seekers and refugees, and factors related to the use of interpreters in Finnish health care. Second, in the methodological part, the aim was to identify the factors related to the use of interpreters in health research.

2 PRIVACY OF SOMALI ASYLUM SEEKERS AND REFUGEES IN HEALTH CARE

This chapter describes the framework of this study. The framework is based on the national and international guidelines and agreements, legislation, statistics, and on a systematic literature search conducted in scientific databases. The main concepts of this study are privacy, Somali refugee, Somali asylum seeker and interpreter. (Table 1.)

Table 1. Definition of the concepts used in this study

| Concept | Definition in this study |
|-----------------|---|
| Privacy | Part of patient's rights to good health care. Individually experienced, culturally defined, situationally dependent, involving an ongoing dialectic process with the surrounding world. (Leino-Kilpi et al. 2001, Heikkinen 2007) |
| Somalia | Land of Somalia, situated in the horn of Africa, has a land area of 637,657 km ² and a population of 11,040,152 (UNdata 2017), including Somaliland, a self-declared state since 1991, is internationally recognised as an autonomous region of Somalia (Somaliland Government 2016). |
| Somali language | Language spoken in Somalia, including all the dialects |
| Somali | Person originally from Somalia, including members of all clans and minority groups |
| Somali patient | Somali person, regardless of the immigration status, using health care services as a patient |
| Refugee | Person who already has been granted protection based on the Convention and Protocol Relating to the Status of Refugees: someone who "owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality, and is unable to, or owing to such fear, is unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it" (UNHCR 1951) |
| Asylum seeker | Person claiming international protection based on the Convention and Protocol Relating to the Status of Refugees, but who has not yet been granted refugee status. (UNHCR 2017b) |
| Interpreter | Person who translates oral language into another as a professional |
| Translator | Person who translates written language into another as a professional |

The database search was carried out during the different parts of the study and updated in 2018 for this framework. It was conducted in Medline (National Library of Medicine) and CINAHL (Cumulative Index to Nursing and Allied Health Literature) databases, covering the years 2000–2018. The search was conducted in two parts, first the part related to the privacy of Somali asylum seekers and refugees in health care, and the use of interpreters in health care was conducted. The search terms were: privacy, Somali, asylum seekers or refugees, interpreter. Privacy was also searched using its related concepts: confidentiality, dignity, autonomy, integrity, secrecy and trust. The search terms were used in various combinations in order to get a wide view of the publications. Secondly the part related to health research with asylum seekers was conducted. The search terms were: asylum seeker, interpreter, health research and research method, which were combined in order to get a wide view of the publications. (Table 2.)

Table 2. Database search

| | | Search terms and combination Limits: years 2000-2018, adults | | Hits | Total of hits |
|---|---|--|--|-------------|----------------------|
| Part 1: Privacy of Somali asylum seekers and refugees in health care | | | | | |
| Databases: Medline CINAHL | Privacy (OR Confidentiality OR Dignity OR Autonomy OR Integrity OR Secrecy OR Trust) NOT (Electronic* Technolog* Biobank*) | AND | Somali OR (Asylum seeker* OR refuge*) OR Interpreter (NOT sign language) | 281 | 370 |
| | Somali AND (Asylum seeker* OR refuge*) | AND | Privacy OR Interpreter (NOT sign language) | 25 | |
| | Interpreter NOT Sign language | AND | Somali* OR (Asylum seeker* OR refuge*) | 64 | |
| | Part 2: Health research with asylum seekers | | | | |
| | Asylum seeker* OR interpreter | AND | Health research OR Research method* | 86 | 86 |

2.1 Privacy in health care and nursing

Privacy in health care and nursing is discussed first by focusing on the concept of privacy in general, and secondly, as a key element in health care and nursing.

2.1.1 Concept of privacy

Privacy, as a noun, is defined as “a state in which one is not observed or disturbed by other people” and as “a state of being free from public attention” (MOT Oxford Dictionary of English 2005). It is also defined to be a condition of being private, withdrawn or secret (Collins English Dictionary 2017). According to Cambridge Dictionary (2017), privacy is seen as a “right to keep personal matters and relationships secret” and as a “state of being alone”.

According to Rawnsley (1980), the word privacy derives from the Latin word “privo” meaning “to deprive”. It was originally used as a military term, private, meaning “to be deprived of status or rank”. Privacy has its roots in the ancient Greek philosophy, where Aristotle made a distinction between the public life associated with political life, and the private life associated with domestic life. It appeared in legal text in 1890, when it was included in American law and was considered as a right to be let alone (Warren & Brandeis 1890).

There is no one universal definition for the concept of privacy. Heikkinen (2007) identified three main difficulties in defining the concept of privacy. Firstly, as an abstract concept, privacy has a variety of meanings starting from the unit experiencing it. Privacy can be seen as a right, claim, situation, form of control, value (McParland et al. 2000b), or need (Westin 1968, Westin 2003). Secondly, it is emotive, irrational in nature and intimately related to the self, and thirdly, it reflects the changing standards, fashions and morals of society (Heikkinen 2007). However, there are certain elements, which are common for most definitions of privacy. First, privacy is linked with being a person and being or not being in interaction with others (eg. Westin 1968, Altman 1976, Burgoon 1982, McParland et al. 2000b, Margulis 2003a, Margulis 2003b, Woogara 2005, Heikkinen 2007, Beauchamp & Childress 2009). Secondly, it is related to control or self-regulation (Westin 1968, Altman 1976, Laufer & Wolfe 1977, McParland et al. 2000b, Margulis 2003a, Margulis 2003b, Woogara 2005, Heikkinen 2007, Beauchamp & Childress 2009). Thirdly, privacy is related to the culture (Westin 1968, Altman 1976, Laufer & Wolfe 1977, Westin 2003).

Privacy can be described as an ideal, desired state or as an achieved state (Altman 1976). It is a dynamic process, meaning privacy can be regulated to

serve momentary need, and a non-monotonic function, meaning the level of privacy may vary between too little privacy into too much privacy. When the desired state of privacy and the achieved state of privacy are equal, there is an optimum state of privacy, if not, there is either too much or less achieved privacy than is desired (Westin 1968). Too much privacy can lead to seclusion from others, too little privacy to stigmatising or embarrassment (Margulis 2003a).

Privacy is usually seen in a positive perspective, however, privacy can also support illegitimate activities (Westin 1968), vandalism (Altman 1976) or deception and lying (DePaulo et al. 2003). DePaulo et al. (2003) argue, that deception can be used to protect privacy, claims to privacy can provide the latitude to lie, and sharing private information exclusively with someone, can be hurtful to those who are not selected to share the information.

Related concepts

In literature, privacy is related to several concepts, such as confidentiality, trust, dignity, autonomy, integrity and secrecy, which are either used as synonyms or are overlapping in definitions (Pinch 2000, Griffin-Heslin 2005, Heikkinen 2007, Beauchamp & Childress 2009).

Confidentiality has strong association with privacy (Pinch 2000, Leino-Kilpi et al. 2001). Privacy is seen as a more global term than confidentiality, since confidentiality is usually connected only with informational privacy and to what extent someone's information is shared with others (Pinch 2000, Leino-Kilpi et al. 2001, Beauchamp & Childress 2009). Confidentiality is related to a confidential relationship, where the confider has a reasonable or legitimate expectation, that his/her information will not be disclosed without his/her permission. The violation of confidentiality can be done by a member of a confidential relationship, however, the violation of privacy can be done by anyone. (Beauchamp & Childress 2009.)

Trust is related to privacy through confidentiality and confidence (Dinç & Gastman 2012, Ozawa & Sripad 2013, Gonzalez 2017). Trust is associated to be an attitude with confidence in someone (Dinç & Gastman 2012). In health care, the development of trust increases the patient's willingness to open up with privacy (Lu et al. 2014).

Dignity and privacy are interrelated (Walsh & Kowanko 2002, Griffin-Heslin 2005, Woogara 2005). Both privacy and dignity are strongly related to respect. Respect for privacy is considered as one essential element of dignity (Griffin-

Heslin 2005). Dignity is related to physical and social privacy; protection of the someone's privacy protects also his/her dignity. (Walsh & Kowanko 2002, Gallagher et al. 2008.) Dignity can be related to individual or his/her social rank and formal position in life. From the viewpoint of individual, it emphasise self-respect, autonomy and positive self-image. In individual's relation with the society, dignity is seen as respecting and believing in others, giving choices and being valuable in relation to others. (Griffin-Heslin 2005.) Dignity is earned, constructed or built, and for that, it can also be lost (Nordenfelt 2004, Nordenfelt & Edgar 2005, Price 2009), also privacy can be lost (eg. Westin 1968, Margulis 2003a).

Autonomy and privacy have a strong connection, however they also have clear differences. Their main difference is, that autonomy is often seen to involve the self-determination of the individual (McParland et al. 2000a) and is related to intellectual capacity (Ballou 1998) and competence (Ballou 1998, Beauchamp & Childress 2009), to ability to control self, ability to reason (Ballou 1998), to understand and to make decisions (Keenan 1999, Beauchamp & Childress 2009). Privacy however, is seen to be a fundamental right for everyone regardless of one's capacity or competence (Burgoon 1982, Beauchamp & Childress 2009). Regardless of their differences, there is clear connection. The full respect of patient's autonomy includes respecting also patient's privacy (Scott et al. 2003). Since autonomy is connected to the individual's self-determination and decision making (Keenan 1999), increasing autonomy improves individual's possibilities to determine about his/her privacy (McParland et al. 2000a, Scott et al. 2003).

Integrity and privacy have many similarities. They both are closely related to respect, they are described as a state of wholeness and as a personal and territorial space (Randers & Mattiasson 2000, Leino-Kilpi et al. 2001, Randers & Mattiasson 2003, Widäng et al. 2008, Tyreman 2011). The connection between integrity and privacy can be seen in integrity's personal sphere, when it refers to the exposé of the body (Randers & Mattiasson 2003), having control over private sphere, when it refers to maintaining private and personal information or visual privacy, and informational confidentiality, when it refers to confidence given to the someone over private information (Widäng et al. 2008). Integrity is also related to same concepts as privacy: dignity, respect, confidence, trust (Widäng et al. 2008) and autonomy (Randers & Mattiasson 2003).

Secrecy and privacy are often considered as synonyms, although they have also differences. They both are related to controlling information from other people (Pinch 2000, Margulis 2003b), they both can be applied at different levels, and

they can be invaded by outsiders (Margulis 2003b). When it comes to the differences, secrecy implies more control than privacy (Margulis 2003b). Secrecy also has a negative connotation and is often associated with morally bad information, or a risk of stigmatization upon its disclosure (Pinch 2000). Privacy however, relates more to a legal right to be free from invasion and has a consensual basis in society (Pinch 2000, Margulis 2003b).

Privacy and culture

In this study, a special attention is given to the cultural context of privacy. Laufer & Wolfe (1977) include cultural elements of privacy into the environmental dimension, which also includes interaction between the social arrangements and physical settings, and the stage of the life cycle. Inside culture, every society and its socio-cultural and environmental factors set norms for privacy (Westin 2003). Cultural identity influences family and privacy boundaries (Hong 2017), and different cultures have different patterns and forms of privacy (Hall 1966, Altman 1976, Leino-Kilpi et al. 2003, Lemonidou et al. 2003, Schopp et al. 2003). Cultural norms limit the perceived options available to any given person or group within the culture. The form and quantity of options is related to the individual's or group's position within the community. Changes in social life affect the perception of privacy. Throughout life, individuals take on different roles, which allow for, inhibit or expose them to new privacy situations. The changes that occur in society might also result in conflicts between learned patterns of privacy and emergent life styles, mores and technologies. (Laufer & Wolfe 1977.)

2.1.2 Privacy as a key element in health care and nursing

Privacy is recognised in different sciences, such as social and behavioural sciences (eg. Laufer & Wolfe 1977, Margulis 2003a, Westin 2003), politics (eg. Westin 2003), legal science (eg. Warren & Brandeis 1890, Westin 1968), and economics and business (eg. Culnan & Bies 2003). In health care, including nursing, privacy is recognised as key element (Leino-Kilpi et al. 2001, Beauchamp & Childress 2009) emphasised in national and international declarations of patients' rights (WHO 1994, Act on the status and rights of patients 785/1992) and ethical codes (eg. ICN 2012, Finnish Nursing Association 2016). Respecting privacy of the patient is one of the rules of good nursing practice (McParland et al. 2000b) and a part of clinical role of the nurse (Mendes et al. 2015). Patients' privacy has a significant relation between with patients' satisfaction (Nayeri & Aghajani 2010).

Respect and protection of privacy is considered to be important in the relationship between the health care professional and patient. Due to perceived lack of privacy, patients might withhold some information from health care professionals and may be reluctant to be examined (Lin & Lin 2011). In health care, patients are placed in a position of having to share their privacy, in order get a valued outcome, such as treatment from health care (Stone-Romero et al. 2003). For that, it is argued, that some level of disclosure of privacy is accepted in health care (Woogara 2005), however, the vulnerable position of the patients may affect on their ability to control their privacy, which might lead to breach of privacy (McParland et al. 2000b).

Privacy is individually experienced, situationally dependent and involves an ongoing dialectic process with the surrounding world. Maintaining privacy can be grouped into internal and external factors. Internal factors refer to a person (nationality/culture, gender, age, duration of hospitalisation, state of illness, work experience), while external factors refer to infrastructure factors (health care resources, health care management, nursing model, environmental arrangements). (Heikkinen 2007.)

Dimensions of privacy

In Western cultures and nursing research, privacy is usually described through four dimensions: physical, psychological, social and informational (Burgoon 1982, Parrot et al. 1989, Leino-Kilpi et al. 2001). *Physical privacy* refers to personal space and territoriality (Leino-Kilpi et al. 2001). Personal space is an invisible space surrounding the individual separating people from one another (Sommer 1969). Territoriality refers to a physical place, in which the individual can control the presence of other people (Leino-Kilpi et al. 2001), and which gives the person an opportunity to be alone if desired (Lynam & Scott 1967, Altman 1976). Physical privacy provides a boundary from being seen, heard or touched by someone else (Parrot et al. 1989). *Psychological privacy* refers to individuals' ability to control cognitive and affective inputs and outputs, to think and form values, beliefs or attitudes. It also concerns individuals' right to control with whom, and when, they will share thoughts, feelings or intimate information. It spares individual from embarrassment and humiliation. (Burgoon 1982.) *Social privacy* refers to individuals' ability and effort to freely control social contacts with others (Westin 1968, Altman 1976). It is defined as both individual and group state (Burgoon 1982). Social privacy has been defined based on different distances or categories (Hall 1966, Westin 1968) and it is related to social and cultural norms (Laufer & Wolfe 1977, Leino-Kilpi et al. 2001). *Informational*

privacy refers to individuals' right to determine the level of personal information revealed to others (Burgoon 1982).

Privacy and culture in health care

Definitions of privacy in health care, including nursing, are guided by the cultural values (eg. Leino-Kilpi et al. 2003, Lemonidou et al. 2003, Schopp et al. 2003, Monshi & Zieglmayer 2004, Pau Le Low et al. 2006, Özturk et al. 2014). Studies conducted in health care and nursing in non-Western cultures show differences in perceptions and values of privacy compared to Western cultures (Nayeri & Aghajani 2010, Akyüz & Erdemir 2013, Özturk et al. 2014). Understanding these differences is essential for health care professionals, since there is a direct and significant relation between respecting privacy and patients' satisfaction (Nayeri & Aghajani 2010) and the Western view of protecting privacy can cause discomfort in non-Western cultures (Monshi & Zieglmayer 2004). This study focuses on Somali culture, as a collective and Muslim culture. Studies conducted in Muslim cultures, emphasizes the physical privacy (Akyüz & Erdemir 2013, Özturk et al. 2014). Especially bodily privacy is considered very important in Islam, and gender-concordant care is emphasised. Muslims, both men and women, are expected to dress modestly in order to protect their bodily privacy (Mohammadi et al. 2007, Yosef 2008, Padela et al. 2011). Studies conducted in the hospital environment in Muslim cultures indicate that respect of privacy is considered weak or average according to half of the patients in the emergency department (Nayeri & Aghajani 2010), while in the surgical ward, patients have mostly been satisfied with their physical privacy (Akyüz & Erdemir 2013). Cultural norms are important also in terms of informational privacy. In Islam, women might not be allowed to make decisions without consulting their husband or other male family member. When women value this cultural or religious norm and agree to this practice, it is their autonomous decision to not make the decision on their own. (Miklancie 2007.) Informational privacy in Muslim cultures is important, and hospitalised patients have been reported to be worried about their personal information. (Akyüz & Erdemir 2013).

2.2 Somali asylum seekers and refugees as patients

This chapter describes Somalia and Somali people, their health beliefs, Somali people as asylum seekers and refugees, and their health and health care services. Somali patients' privacy and favourable health care services as well as their challenges in health care are also described. Finally, the use of interpreters in health care is described.

2.2.1 Somalia, the land and its people

The country “Somalia” got its name from the people living in that area, called Somali. The word “Somal” derives from the words “so” (to go) and “mal” (to milk). This etymology is unconfirmed; however, there is a connection with a tribal chief called Samal, who got his name after ‘putting out the eye’ (samala) of his brother. (Lewis 1994.) The majority of the people living in Somalia are called Somali (Metz 1993). Besides the majority ethnic population, there are several minority groups in Somalia. It is estimated that as many as one in three people living in Somalia belong to minority groups. These groups, including Bantu, Bravenese, Rerhamar, Bajuni, Eyle, Galgala, Tumul, Yibir and Gaboye, continue to live in poor conditions and suffer from numerous forms of discrimination and exclusion (UN Office for the Coordination of Humanitarian Affairs 2002). The main religion of Somalia is Islam. It is estimated that 99.8% of the population is Muslim, most of them Sunni Muslims (Lewis 2008).

In this study the term “Somalia” is used to refer to one country, including Somaliland, and the term “Somali” to refer to all people coming from Somalia or Somaliland, including all the members of the minority groups. Somali patients in this study, includes all Somali people using health care services as patients regardless of their immigration status, and Somali asylum seekers and refugees are used when focusing on these special groups. (Table 1.)

The structure of Somali society is based on patriarchal lineage. The lineage is based on six clan-families, divided into clans and further into sub-clans and diya-paying groups, ending in extended families. One of the most important alliances in the lineage is the diya-paying group, which includes 200-2,000 families. Diya-paying groups are the smallest political units to which all Somali belong and whose members are pledged to support each other and to pay and receive “blood compensation”, diya. The family tree identifies its members not only socially, but also politically and economically, and marriages between different sub-clans, clans or families used to be organised to strengthen the complex alliance between the groups. (Lewis 2008.) The family acts as a safety net. It ties people together and gives support in the event of problems of any kind. Family can also be a source of conflicts, mainly related to the high number of divorces. (Svenberg et al. 2009.)

As the patriarchal lineage and diya-paying groups indicate, Somali culture is a collective culture, where the needs of the group (e.g. family) are more important than the needs of individuals. In order to highlight the patriarchal lineage and the importance of family, Somali children are given three names, where only the first

name is personal while the second and third names are the names of the child's father and paternal grandfather. (Lewis 1996.)

The Somali language has several dialects. Common Somali, which applies to several sub-dialects, is most widely used and spoken in most parts of Somalia. Even though it is not one single dialect, its speakers can understand each other quite easily. Other bigger dialect groups are Coastal Somali and Central Somali. (Metz 1993.) The Somali language remained unwritten until 1972 when literacy programmes were launched. Somalis have a strong tradition of oral storytelling; especially poetry is a big part of Somali culture. Storytelling has also been a way of getting public respect, especially among men. (Lewis 2008.) The literacy rate of Somalia is low, 37.8% (United Nations Educational, Scientific and Cultural Organization [UNESCO] 2016).

2.2.2 Health believes in Somali culture

Somali culture, as other cultures, have their own believes concerning health. Somalis beliefs about health and health promotion include: Good sanitation, adequate nutrition and exercise, the role of religion, access to health care and medication (Carroll et al. 2007b), traditional remedies and rituals (Upvall et al. 2009, Lightfoot et al. 2016). The traditional Somali lifestyle, with features such as healthy eating (fresh organic food, vegetables) and an active lifestyle (manual labour, working in the fields etc.), promotes health (Lightfoot et al. 2016). The family acts as safety net providing support (Svenberg et al. 2009) and socialization, and the interconnected nature of the community helps Somalis to prevent and cope with an illness (Hill et al. 2012, Bettmann et al. 2015, Lightfoot et al. 2016, Markova & Sandal 2016).

In health, health beliefs and health practices, the religion, Islam, has an important role (Carroll et al. 2007b, Svenberg et al. 2009, Lightfoot et al. 2016, Markova & Sandal 2016, Wolf et al. 2016). Religion and faith have a big role for Somali people, being part of self-identity, and representing comfort and security (Svenberg et al. 2009). Reading the Quran (Bettmann et al. 2015, Lightfoot et al. 2016, Markova & Sandal 2016) is used both to prevent and treat illnesses (Lightfoot et al. 2016). The value of health is a religious belief (Lightfoot et al. 2016), regardless of the medical care, the outcomes are determined by God (Hill et al. 2012). High religiousness has been estimated to be a protecting factor for older Somalis, as exposure to severe war trauma was not associated with high levels of PTSD or somatization symptoms among highly religious refugees (Mölsä et al. 2017).

2.2.3 Somali asylum seekers and refugees

Somali migration has a long history starting with the colonial period, 1897-1960, when Somalis were settled abroad. After Somalia gained independence in 1960, wars and famine have forced Somalis to flee their country. In 1988, a civil war started, and Siad Barre, who had ruled Somalia for 22 years, was overthrown and went into exile in 1991. The civil war and clan violence related to that caused large movements of people, which have continued until the present day. It is estimated that today, more than 2 million Somalis are either refugees, asylum seekers or internally displaced persons. (UNHCR 2017c.)

Somalia and Finland had a shared history even before Somali refugees started immigrating to Finland. During the 1980s, Finland was giving development assistance to Somalia and was active in establishing the tuberculosis prevention programme in the country. In 1986, Finland was the fourth biggest aid giver to Somalia after Italy, USA and the World Bank. In 1990, Finland ended the development assistance to Somalia due to the civil war. (Aallas 1991.)

Definition of asylum seeker and refugee

The focus of this study is on Somalis in the position of asylum seekers and refugees. Asylum seekers and refugees have a lot in common, and the terms are often confused. They have both fled from their country of origin, to seek international protection.

A refugee is a person who has already been granted protection based on the Convention and Protocol Relating to the Status of Refugees (UNHCR 1951) (Table 1). A person can usually obtain refugee status by immigrating to a country based on an annual quota, family reunification programmes or by the decision for asylum application. In Finland, the annual quota is defined by the Ministry of Internal Affairs. Since 2001, the number of quota refugees accepted by Finland has been 750 per year. In 2014 and 2015, the number was increased to 1050, due to the situation in Syria. The quota refugees are selected with the co-operation of UNHCR and Finnish immigration services, and they are placed in municipalities, with the same rights as Finnish residents. (Finnish Immigration Service 2017a.)

An asylum seeker is a person who applies for international protection when entering the host country, but whose claim for refuge has not been definitively evaluated (UNHCR 2017b). (Table 1.)

Somali asylum seekers and refugees in Finland

Somali asylum seekers started to enter Finland in 1990. Since then, Somalis have been one of the largest asylum seeker and refugee groups in Finland. From 1990 into 2017, the annual number of all asylum applications has mainly varied between under 1,000 and over 5,000. Finland has received Somali asylum seekers yearly, with a varying number of fewer than 100 applications up to more than 500 applications per year, and Somalis have nearly always been one of the largest asylum seekers groups. In 2008 and 2009, the number of Somali asylum seekers was higher than usual: at that time, Finland received a total of 2,361 Somali asylum seekers in two years. (Finnish Immigration Service 2018.) (Appendix 1.) Besides the asylum procedure, Somali refugees immigrate to Finland mainly through official family reunification programmes. In 2007-2017, nearly 6,000 Somalis were given resident permit in Finland, mainly based on family reunification (Finnish Immigration Service 2018). (Appendix 1.)

Pre- and post-settlement experiences of asylum seekers and refugees

In this study, asylum seekers' and refugees' experiences are divided into pre-settlement and post-settlement experiences (Figure 1). Pre-settlement experiences include experiences before and during the flight from the home country. Post-settlement experiences include experiences in the new country.

The pre-settlement experiences place asylum seekers and refugees in a vulnerable position. Pre-flight experiences, such as war and persecution, and forced flight, leaving relatives and friends behind, can be traumatic. Besides, during the flight, especially women are at risk of becoming victims of sexual violence. (Byrskog et al. 2014.)

Post-settlement experiences separate the experiences of refugees and asylum seekers. When both groups face the challenges of adaptation to the host country, asylum seekers have to go through the asylum application procedure. Adaptation to a new country and new culture is challenging; both refugees and asylum seekers face language barriers, loss of social and cultural capital, discrimination, racism, stigma and geographical, climate and food differences (Fang et al. 2015). Besides adaptation to the new country and culture, asylum seekers have to follow their application procedure, conducted in a strange language, with the uncertainty of the future decision and its effect on their lives. The asylum application procedure itself have been recognised to have a negative impact on asylum seekers' health and quality of life. The asylum interview might trigger posttraumatic intrusion for traumatised asylum seekers (Schock et al. 2015), and

a long procedure is linked with increasing health problems (Laban et al. 2008). The change of status into residence permit has been recognised to be beneficial for health (Lamkaddem et al. 2015).

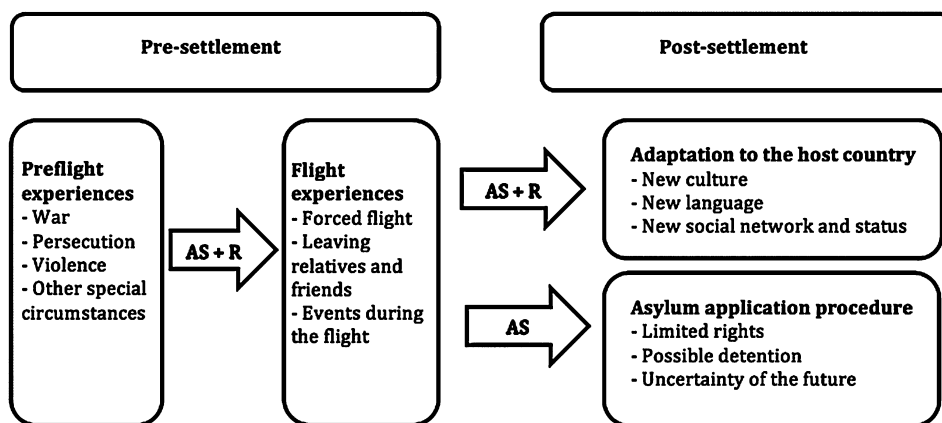


Figure 1. Pre- and post-settlement experiences of asylum seekers (AS) and refugees (R)

Asylum application procedure

The asylum application procedure starts when a person applies for international protection on arrival to the host country. In different countries, the protocol of the asylum application procedure may vary; however, asylum is usually applied from the police, immigration authorities or border authorities (Asylum Information Database [Aida] 2016; Finnish Immigration Service 2017b). Asylum seekers are interviewed for the application, where the asylum seeker demonstrates his/her eligibility for the need of international protection (Finnish Immigration Service 2017b). In order to prove the eligibility for international protection, a medical evaluation is usually suggested. This includes both medical and psychological evaluations. (Lustig et al. 2008, Scruggs et al. 2016.) The decision on the application is made by immigration authorities (Finnish Immigration Service 2017b).

The asylum application procedure can be complex and varies in different countries (Aida 2016). In Finland, the decision about the procedure type (e.g. normal or urgent/accelerated procedure) is made mainly based on the arguments for need of international protection in the application. The application can also be left unprocessed (non-examined applications) for example, if the applicant has applied for asylum or has been granted asylum or other protection in another safe country (Finnish Immigration Service 2017b). The procedure ends when the asylum seeker is either granted authorisation to stay in the host country (positive

decision) or is deported from the host country because of a negative decision. In Finland, asylum seekers may appeal against the decision to the Administrative Court and seek leave to appeal from the Supreme Court. (Finnish Immigration Service 2017b.) In 2016, the average duration of the asylum application procedure in Finland was 263 days (Finnish Immigration Service 2017c), and a total of 28,208 decisions on asylum applications were made (Finnish Immigration Services 2018). (Table 3.)

In Finland, the rights of asylum seekers are described in the Act of the Reception of Persons Seeking International Protection (746/2011). Asylum seekers have the right to information and legal advice during their procedure, accommodation, education and working. They also have the right to social care services including economic support (Act on the reception of persons seeking international protection 746/2011), which is usually smaller than the support for residents (Ministry of Social Affairs and Health 2017), and to free basic health care services (Act on the reception of persons seeking international protection 746/2011). Internationally and nationally, special attention has to be paid in health care to victims of torture or other severe trauma (Ministry of Social Affairs and Health 2017).

Table 3. Decisions on asylum 2016 (modified from Finnish Immigration Services 2018)

| Decision | Total | |
|---------------------------|------------------------------------|-----------------------------|
| | Convention status | 4,586 |
| | Subsidiary protection | 1,739 |
| Positive decisions | Humanitarian protection | 50 |
| | Other residence permits | 1,370 |
| | Total of positive decisions | 7,745 |
| | Negative decision | Total of negative decisions |
| Annulment of application | Total annulment of applications | 3,855 |
| Non-examined applications | Total of non-examined applications | 2,326 |
| Total | Total of decisions | 28,208 |

2.2.4 Health and health care services of Somali asylum seekers and refugees

Health status of Somali people

Studies conducted on Somali people's health, has either been done focusing on Somali population, including all kind of immigration status, or specifically

focusing on the Somali asylum seekers and refugees. In many studies, Somali population have been reported to have a high prevalence of diabetes (Laatikainen et al. 2012b, Wieland et al. 2012, Njeru et al. 2016) and obesity (Kinzie et al. 2008, Laatikainen et al. 2012a, Dharood et al. 2013, Njeru et al. 2016). In Finnish studies, Somalis, specially Somali men, consider their current health status and their quality of life to be good (Koskinen et al. 2012). Studies also indicate, that mobility limitations are more prevalent among Somali origin population compared to general Finnish populations (Rask et al. 2016). One of the biggest issues affecting Somali women's health is female circumcision. Female circumcision causes health problems (Koponen & Mölsä 2012), not only immediately after the procedure but also later in life, such as urinating problems, difficulties with menses, pain with intercourse (Brown et al. 2010, Jo Connor et al. 2016), delivery challenges (Brown et al. 2010) and negative effect on sexual relationship (Jo Connor et al. 2016).

When focusing on Somali refugees and asylum seekers, their health status is related to pre-settlement and post-settlement experiences. Somalis have pre-settlement traumatic experiences, such as warfare, ethnic discrimination, death of loved one (Matheson et al. 2008, Jorden et al. 2009, Svenberg et al. 2009, Shannon et al. 2015) or other forms of physical and psychological violence and torture (Byrskog et al. 2014, Mölsä et al. 2014). Due to the traumas caused by pre-settlement and forced flight events, Somali asylum seekers and refugees suffer from posttraumatic stress disorder (Mölsä et al. 2017) and depression (Kuittinen et al. 2017). They are significantly likely to experience poor general health status (Mölsä et al. 2014), high levels of mental distress (Jorden et al. 2009, Mölsä et al. 2014, Fang et al. 2015), poor levels of health-related quality of life and subjective quality of life (Mölsä et al. 2014). Traumas are also related to functioning (Lee Robertson et al. 2016) and acculturation stress (Jorden et al. 2009). Somali asylums seekers have been reported to be suffering from sleeping difficulties, general pain, chest pain, headache, stomach ache, vision problems, stress, forgetfulness and depression (Ekblad et al. 2012, Shannon et al. 2015). Somali patients are considered being in a difficult psychological situation (Ekblad et al. 2012) and being sad and angry (Shannon et al. 2015).

Pre-settlement events affect the building of a new life in the host country. Even though Somali asylum seekers mainly feel secure and calm after the settlement and have some hope for the future, the current life situation of Somali asylum seekers is characterised by insecurity, uncertainty, anxiety and ignorance of their new setting (Ekblad et al. 2012), stigmatised refugee identity, unmet expectations

and difficulties in settling in the host country (Warfa et al. 2012). These are linked with various psychological problems (Warfa et al. 2012).

Post-settlement has enabled changes in traditional gender roles (Carroll et al. 2007b, Johnson-Agbakwu et al. 2014). These changes foster new dynamics in shared decision-making within the household. Even though Somali men are reported to value shared decision-making with their wives, they have expressed frustration about losing control of their households. (Johnson-Agbakwu et al. 2014.) According to Nilsson et al. (2008), Somali women with greater proficiency in English are more likely to experience both psychological abuse and physical aggression from their partners. From another point of view, post-settlement has benefits for health. Somali women have reported a need for personal space and freedom, increasing opportunities for education (Carroll et al. 2007b), and enabling women and men to talk more freely about sexual health (Kingori et al. 2016).

Finnish health care services for asylum seekers and refugees

Asylum seekers are entitled to health care services according to European Directive 33/2013/EU (European Commission 2013) and Finnish legislation (Health care act 1326/2010, Act on the Reception of Persons Seeking International Protection 746/2011). Adult asylum seekers are entitled to urgent treatment and other health care services deemed necessary, which include also maternity health care, urgent oral health care, mental health care, substance abuse care and psychosocial support. Children are entitled to all health care services. A special attention has to be given to asylum seeker in vulnerable position, such as pregnant women or traumatised people. (Act on the Reception of Persons Seeking International Protection 746/2011.) Urgent health care include health care needs, which requires immediate interventions and where treatment cannot be postponed without risking the worsening of the condition or further injury (Health Care Act 1326/2010).

Health care services for asylum seekers are provided by the reception center, where asylum seekers are accommodated. The reception centers are operated either by the government, municipality or third section such as Red Cross, however, the costs are all compensated by the state. (THL 2018a.) Health services in reception centers include health information, health interview, vaccinations, screening of infectious diseases and urgent health care, provided by health care professionals. Health information is given to asylum seekers after two weeks of their arrival to Finland. The information, given by a public health nurse,

includes information on the asylum seekers' rights to health services, Finnish health care system, and common health care problems. The information is given with the help of interpreters. The nurse or public health nurse of the reception center also meets the asylum seekers for a health interview within two weeks of arrival of the asylum seeker. The aim is to evaluate the need for urgent and necessary health services and the risk of infectious diseases. Screened diseases are: tuberculosis, hepatitis B, hiv, syphilis and intestinal parasite. (THL 2018a.) According to recommendation for vaccinations, adult asylum seekers should be provided the essential vaccination for the protection of individual and population. Children asylum seekers are entitled to the all vaccinations according to the national vaccination programme. (THL 2018b.)

Asylum seekers, with positive decision on their asylum application, and refugees are settled to live in municipality and are entitled to the same health care services as other residents of the municipality (Ministry of Social Affairs and Health. 2017).

Both, Somali patients (Koponen et al. 2012) and Somali asylum seekers and refugees as a separated group (Gissler et al. 2006), use health care services more often than native residents. In Finland, asylum seekers pay a lot of visits to the health care services for similar reasons than residents, such as respiratory inflammations, diarrhea, pain, dental pain, injuries and mental health problems (Pirinen 2008). Somali asylum seekers have reported to use a lot of mental health services (Pirinen 2008), Somali patients, however, have been reported to have lower utilization of mental health care than the native group in Norway (Abebe et al. 2017). Somali patients use mostly the services of physicians in public health care centers (Koponen et al. 2012) and they have a higher emergency primary health care contact rate than native residents (Sandvik et al. 2012). A high percentage of their contacts occurs during the night and is related to different kinds of pain (Sandvik et al. 2012).

Privacy of asylum seekers and refugees in health care

There are only few studies mentioning the privacy of asylum seekers and refugees in health care. Asylum seekers and refugees have experienced lack of trust concerning confidentiality on the part of health care professionals (Asgary & Segar 2011, Jonzon et al. 2015) and the interpreter (Jonzon et al. 2015). Asylum seekers have been reported to have common beliefs that information on their health assessment is shared with migration authorities, and the information could influence their asylum process and chances of obtaining a resident permit

(Jonzon et al. 2015). Besides lack of confidentiality towards health care professionals and interpreters, secrecy is kept for social reasons as well. The secrecy is related to specific health issues (such as tuberculosis or cervical cancer), which cause embarrassment, stigma (Fang & Baker 2013) and fear of social isolation that may result if other members of the community are aware of the individual's health issues (Lenette 2015). Health care professionals' respect for privacy reduces patients' embarrassment and encourages patients to share their health issues (Fang & Baker 2013). There are contradicting results on asylum seekers' autonomy in health care. In the UK, asylum seekers and refugees have been reported to have increased autonomy in health care in the host country compared to their country of origin (Verran et al. 2015). Another study, conducted in Sweden, reports decreased autonomy when patients have felt forced to attend health assessment (Jonzon et al. 2015).

2.2.5 Somali patients' privacy and favourable health care services

There are only few studies mentioning the privacy on Somali patients. Privacy is usually discussed within its related concepts, such as trust, confidentiality, secrecy and autonomy. The level of trust and confidentiality is reflected by pre-settlement events, and it is seen to cause reluctance to visit health care services (Fang et al. 2015).

There are differing reports on sharing information between Somali patients and health care. Some studies indicate that Somali patients do not want to share their illness with anyone except a trusted member of their community (eg. Piwowarczyk et al. 2014, Wolf et al. 2016), whereas others report that private information is rather shared with a health professional than with general community members (Dahal et al. 2014). When it comes to trust, Somali patients have been reported to be unwilling to share information with the interpreter (Upvall et al. 2009) and not trusting the interpreter (Fang et al. 2015).

Privacy is emphasised when it comes to reproductive health care and mental health care. Talk and examination related to sexuality and issues related to it are considered private (Jo Connor et al. 2016, Kingori et al. 2016, Hawkey et al. 2017), stigmatising (Kingori et al. 2016) and shameful (Kingori et al. 2016, Hawkey et al. 2017, Metusela et al. 2017, Ussher et al. 2017), which leads to inadequate knowledge of sexual and reproductive health (Metusela et al. 2017, Ussher et al. 2017) and preventive screening practices (Metusela et al. 2017). In Somalia, pregnancy is considered as part of health, and delivery is described as a

natural process, controlled by God, with no need for intervention (Hill et al. 2012).

Also mental health issues are considered private, since mental health problems are stigmatised in Somali culture (Hill et al. 2012, Piwowarczyk et al. 2014, Bettmann et al. 2015). Somalis tend to hide their emotional problems to avoid becoming labelled as “crazy”, and thus risk being rejected by the community (Hill et al. 2012).

Besides privacy, other qualities associated with a favourable health care experience included effective verbal and nonverbal communication (Carroll et al. 2007a, Saadi et al. 2015), feeling valued and understood, availability of female interpreters and clinicians, and sensitivity to privacy for gynaecologic concerns (Carroll et al. 2007a), cultural care (Wolf et al. 2016), respect of Somali culture and community (Wolf et al. 2016), easy transport to health care services (Saadi et al. 2015). The gender of the health care professional should be the same as the patient’s (Degni et al. 2012, Hill et al. 2012, Odunukan et al. 2015, Wolf et al. 2016); however, acculturation to a new country and culture leads to changes in how the gender differences are viewed, and they are becoming less important (Johnson-Agbakwu 2014, Wolf et al. 2016). In situations where the female patient’s safety is in danger (e.g. during delivery), a male provider is acceptable (Hill et al. 2012). The request for same-gender physician can create challenges in treatment (Degni et al. 2012).

2.2.6 Somali patients’ challenges in health care

Somali patients, including asylum seekers and refugees face many challenges in health care. Studies show lack of knowledge of the health care system, the processes and procedures to access health care services, problems with long waiting times for health care services (Fang et al. 2015) and difficulties in accessing health care, such as transportation problems (Hill et al. 2012). At the health care encounter, Somalis have experienced the duration of the encounters to be too short (Fang et al. 2015), having an unfamiliar health care provider and having to repeat their histories over and over (Hill et al. 2012), cultural barriers (Fang et al. 2015), language and communication barriers (Hill et al. 2012, Shippee et al. 2012, Fang et al. 2015), poor availability of interpreters (Fang et al. 2015), unwillingness to share information with the interpreter (Upvall et al. 2009), mistrust towards the interpreter (Fang et al. 2015), mistrust towards the benefit of health care or interventions (Hill et al. 2012, Dahal et al. 2014, Wojnar 2015) and different perception of time (Upvall et al. 2009, Hill et al. 2012).

Especially when it comes to pregnancy, women have been reported to have mistrust towards western medicine and its methods, and having more faith in God than in science (Hill et al. 2012). Somali patients have been reported to feel uninformed, vulnerable, disrespected and misunderstood. Some patients have felt pressured to agree to suggested treatments, and few health care professionals take the time to explain the informed consent procedure to the full satisfaction and understanding of the patients. (Wojnar 2015.)

The nurse-patient relationship with Somali patients depends on the health care professionals' understanding of patients' history, culture, religion and the changes in their lives in the new country. Nurses and midwives consider building a relationship with Somali women in reproductive health care challenging due to traumas, sexual abuse, mistrust and cultural differences. Compared to physicians, nurses have reported to have a better relationship with Somalis. (Degni et al. 2012.) Midwives have reported important factors in taking care of Somali women: focusing on the individual woman beyond ethnicity and cultural differences, establishing a trustful relationship, achieving cultural competence, facing a different view of asking about and discussing sensitive health issues, having a shared language, patience and networking (Byrskog et al. 2015). Home visits to Somali women are shown to be a good opportunity for building up a relationship (Degni et al. 2012). One of the most reported challenges are related to linguistic challenges, such as language barriers (Degni et al. 2012, Lazar et al. 2013), trust towards interpreters and patients' willingness to use non-professional interpreters (Degni et al. 2012, Lazar et al. 2013).

2.2.7 Use of interpreters in health care

An interpreter is defined to be “a person who interprets, especially one who translates speech orally” (MOT Oxford Dictionary of English 2005). A professional interpreter is considered to be an interpreter who is paid for his/her interpretation services and follows and practices the national code of ethics of interpreters, including professional confidentiality (Translation Industry Professionals 2013). The educational background of the interpreter varies from informal education given by an independent interpreter service to formal University level education (Finnish Association of Translators and Interpreters 2017). In this study, the term interpreter is used for a person who translates oral language, and the term translator is used for a person who translates written language. (Table 1.)

Interpreters in health care

In health care an interpreter is needed to reduce language barriers between the health care professional and patient. The use of interpreter can be justified on behalf of the patient and the health care professional. The patient has the right to be informed about his/her health and treatment and to make decisions about his/her treatment. The information should be given in a way that the patient understands, with the help of an interpreter if possible. (Act on the status and rights of patients 785/1992.) The nurses have the responsibility to ensure that the patient receives information in a culturally appropriate manner on which the patient can base his/her consent for care and treatments (International Council of Nurses 2012). The use of interpreters can be seen to assure the nurse that he/she has acted appropriately according to his/her responsibility.

The use of professional interpreters improves the quality of clinical care of patients by decreasing communication errors, increasing patient comprehension (Karliner et al. 2007, Perez et al. 2016), equalising health care utilisation, improving clinical outcomes (Karliner et al. 2007), increasing patients' (Karliner et al. 2007, Ramirez et al. 2008, Perez et al. 2016) and health care professionals' (Bagchi et al. 2011) satisfaction with communication, improving patients' satisfaction with clinical services (Karliner et al. 2007, Hadziabdic et al. 2009), improving health care access (number of diagnostic tests conducted, rates of side effects explanation, referral to follow-up appointments) (Ramirez et al. 2008) and decreasing readmission rates (Karliner et al. 2017).

Even though the benefits of the use of interpreter are acknowledged, interpreters are underused in health care (Diamond et al. 2008, Ramirez et al. 2008, Kale & Syed 2010, Butow et al. 2011, Fryer et al. 2013, Silva et al. 2015, Perez et al. 2016, Van Rosse et al. 2016). The reasons why health care professionals do not use interpreters are related to multiple problems in interpreting services and availability of interpreters (Hadziabdic et al. 2010, Kale & Syed 2010), the costs of implementing interpreter services (Ramirez et al. 2008, Anders et al. 2013), lack of skills or education on how to work with interpreters (Baurer et al. 2014), considering it to be time-consuming (Diamond et al. 2008, Ramirez et al. 2008, Kale & Syed 2010, Anders et al. 2013, Perez et al. 2016), difficulties judging the necessity of an interpreter (Kale et Syed 2010), health care professionals' own language skills (Anders et al. 2013, Baurer et al. 2014) or the use of other bilingual health care staff (Ramirez et al. 2008, Butow et al. 2011, Silva et al. 2015), patients' preference or language skills (Anders et al. 2013), risk of patients safety (Anders et al. 2013), mistrust towards the interpreter's competence (Anders et al. 2013) and privacy concerns (Perez et al. 2016).

Health care professionals have reported their dissatisfaction with their own competence on working with interpreters (Upvall et al. 2009, Kale & Syed 2010) and it has been reported to be one reason for not using interpreters (Baurer et al. 2014). Time management and setting of an agenda for the encounter are considered more difficult with interpreters than without interpreters (Rosenberg et al. 2007), the rhythm of the encounter is slower (Rosenberg et al. 2007, Fatahi et al. 2008), and health care professionals have less control over the flow of the conversation (Rosenberg et al. 2007, Hsieh & Kramer 2012). The delay between patient's speech and the interpretation makes linking verbal and non-verbal communication challenging (Rosenberg et al. 2007). When using interpreters, an active role is demanded from all participants involved in consultations (Fatahi et al. 2008). The health care professional has to be open to cultural inequalities and recognise consultation through an interpreter as a part the job, including practical issues (Fatahi et al. 2008). Training on how to work with interpreters and use interpreter services helps the health care professionals to understand better the behaviour of the interpreter (Hsieh 2010) and improves the use of professional interpreters (Jacobs et al. 2010, Baurer et al. 2014).

Role of the interpreter

The main role and duty of the interpreter is to be neutral and interpret the spoken message reliably into another language (Fatahi et al. 2008, Rosenberg et al. 2008, Hadziabdic et al. 2009, Fatahi et al. 2010, Hsieh 2010, Hsieh et al. 2010, Hsieh & Kramer 2012). However, studies indicate that the role of the interpreter is more complex (Brisset et al. 2013, Sleptsova et al. 2014). The expectations of the interpreter's role vary from maintaining professional boundaries (Rosenberg et al. 2008, Hsieh & Kramer 2012) into going above and beyond the interpreter's role and being caring (Lor et al. 2016). Interpreters serve as cultural brokers (Rosenberg et al. 2007, Rosenberg et al. 2008, Hsieh & Kramer 2012, Sleptsova et al. 2014, Lor et al. 2016), information gatekeepers (Hsieh & Kramer 2012), clarifiers (Sleptsova et al. 2014), patient advocates (Hsieh & Kramer 2012, Sleptsova et al. 2014), common helpers (Hadziabdic et al. 2009, Lor et al. 2016), mediators or moderators (Hsieh & Kramer 2012), creators of safe environment for the patient (Rosenberg et al. 2008) and as patient's emotional support (Hsieh & Hong 2010, Hsieh & Kramer 2012). Interpreters might also engage in a non-interpretive role, such as the role of health care professional role or patient (White & Laws 2009), or co-diagnostics (Hsieh 2007, Hsieh 2010). There are differences in considering whether interpreters are seen as members of the health care team. Interpreters consider themselves members of the health care team having a shared goal within the health care team (Hsieh et al. 2010); however,

according to health care professionals, interpreters are mainly seen as tools, and their opinions or perspectives are not solicited (Hsieh & Kramer 2012).

The interpreter is expected to have language skills in both interpreted languages and to be proficient in medical terminology (Fatahi et al. 2008, Lor et al. 2016); however, there are concerns, both from the part of patients and health care professionals, about the completeness and accuracy of the information received (Rosenberg et al. 2007, Fatahi et al. 2008, Hadziabdic et al. 2009, Barnes et al. 2011, Krupic et al. 2016) and the risk of clinical errors (Gany et al. 2010). Evaluating the completeness and accuracy of the interpretation is challenging. It is done by evaluating the understanding of the interpreted message (Lor et al. 2016), listening to familiar keywords (Hsieh 2010), comparing the amount and time of interpretation and the original message (Fatahi et al. 2008, Hsieh 2010, Lor et al. 2016), evaluating the amount of follow-up questions by the interpreter, evaluating the logic of the response to an earlier message and by evaluating the length of pauses before interpretation (Lor et al. 2016).

Relationship between the patient, health care professional and interpreter

Building a trusting relationship between the patient and health care professional is more difficult with an interpreter than without an interpreter (Rosenberg et al. 2007, Hsieh & Hong 2010, Barnes et al. 2011, Brisset et al. 2013). The use of interpreters may cause a loss of intimacy between the patient and health care professional (Anders et al. 2013, Brisset et al. 2013), or, sometimes, the relationship between the patient and interpreter is built first, and health care professionals might feel excluded from the interaction (Rosenberg et al. 2007). On the other hand, the interpreter might engage in discussion with the health care professional, excluding the patient from the discussion (Lor et al. 2016). Lack of continuity of interpreters in the nurse-patient-interpreter relationship forces the patients to create a trusting relationship with several interpreters (Fatahi et al. 2008, Hadziabdic et al. 2009, Barnes et al. 2011). Continuity would also benefit the collaboration between the health care professional and interpreter (Hsieh et al. 2010).

Patients perceive the use of interpreter as a disability, creating a feeling of dependency and decreasing privacy in the relationship with health professionals (Hadziabdic et al. 2009). Patients' expectations of the interpreter-mediated encounter with the health care professional are high, but not always fulfilled (Krupic et al. 2016). The challenges patients face are the following: interpreters being late (Krupic et al. 2016) or not showing up at the encounter (Hadziabdic et

al. 2009), interpreters lacking professionalism or acting inappropriately (Krupic et al. 2016), differences in language (Hadziabdic et al. 2009, Fatahi et al. 2010) and mistrusting the interpreter as a result of cultural differences (Fatahi et al. 2010). Mistrusting the interpreter's confidentiality and other fears have an impact on communication (Hadziabdic et al. 2009, Fatahi et al. 2010, Barnes et al. 2011, Krupic et al. 2016), and is one of the biggest reasons for patients' unwillingness to use interpreters (Hadziabdic et al. 2009), or for reliance on non-professional interpreters, such as family members or friends (Ramirez et al. 2008, MacFarlane et al. 2009, Hadziabdic et al. 2010, Kale & Syed 2010, Butow et al. 2011, Fryer et al. 2013, Silva et al. 2015, Van Rosse 2016). However, The use of non-professional interpreters is not recommended because of several reasons, such as lack of competence (Ramirez et al. 2008, MacFarlane et al. 2009, Gany et al. 2010, Butow et al. 2011, Flores et al. 2012), poor communication and negative outcomes, including omission or alteration of information (Silva et al. 2015) and feelings of frustration and hopelessness of the health care professional (Degni et al. 2012). Besides, the use of family members or friends can lead to emotional conflicts within the patient's family or community (Silva et al. 2015) and patients might express less emotional concerns to the health care professional (Ramirez et al. 2008, MacFarlane et al. 2009).

Different interpreting methods

Due to many challenges in using interpreters, different kinds of interpreting, such as telephone interpreting, video interpreting or remote simultaneous medical interpreter (RSMI) methods, are used. In-person interpretation has been reported to result in better patient satisfaction than telephone interpretation (Ramirez et al. 2008), and both patients (Hadziabdic et al. 2009) and physicians (Fatahi et al. 2008, Anders et al. 2013) prefer in-person interpreters to interpretation by telephone. Also interpreters are reported to prefer in-person interpretations with refugees as enhancing the ability to develop trust with the client (Dubus 2016). In-person interpretation has been reported to have a significantly shorter total throughput time than telephonic interpretation and bilingual provider (Grover et al. 2012). However, telephone and video interpreting improve access to professional interpreters and efficiency and reduce reliance on non-professional interpreters (Baurer et al. 2014), and telephone interpretation has been proved to be satisfactory for information exchange (Price et al. 2012) focusing on medical issues (Hsieh & Hong 2010). However, it is insufficient for substantial education (Price et al. 2012) or psychosocial components such as emotional support (Hsieh & Hong 2010, Price et al. 2012). The quality of in-person and video conferencing interpretation has been reported to be similar (Nápoles et al. 2010); however,

another study reports videoconferencing interpretation to be considered more adequate than telephonic interpretation (Price et al. 2012). RSMI has been reported to have potentially few errors and to improve efficiency and patient satisfaction (Leng et al. 2010). It also protects patients' privacy better than in-person interpretations (Gany et al. 2007).

2.3 Health research with asylum seekers as a vulnerable group

In health research, asylum seekers are considered a vulnerable group based on their pre- and post-settlement experiences (Beauchamp & Childress 2009, European Commission Directorate-general for Research and Innovation 2017). This vulnerable position has raised discussion on the ethics of conducting research with asylum seekers (Leaning 2001, Rousseau & Kilmayer 2010, Zion et al. 2010). However, Wilson & Neville (2009) emphasise the importance of giving the vulnerable population a voice. Research should benefit those being researched and the researcher should provide a culturally safe space for dialogue between the participants and researcher. (Wilson & Neville 2009.) The researchers should actively engage with communities in decision-making about the design and conduct of research (WHO 2016), and in the informed consent process (The World Medical Association 2016).

The conduct of health research with asylum seekers often requires an interpreter (e.g. Bhatia & Wallace 2007, Asgary & Segar 2011, Jonzon et al. 2015). Using interpreters impacts the whole research process (Kapborg & Berterö 2002, Wallin & Ahlström 2006, Squires 2009). The role of the interpreter should be invisible throughout the research process, and interpreters' credentials should be described (Squires 2009, Ingvarsdotter et al. 2010, Björk Brämberg & Dahlberg 2013). By acknowledging the impact of interpreters in health research with asylum seekers, the researcher can be sensitive to and respect the communities' cultural, traditional and religious practices (WHO 2016). There are a number of methodological articles focusing on the use of interpreters with immigrants (e.g. Wallin & Ahlström, 2006, Squires, 2008, Fryer et al. 2013, Björk Brämberg & Dahlberg 2013), but none of these focus solely on asylum seekers. Asylum seekers are usually combined with other groups, such as refugees (Fang et al. 2015, Enticott et al. 2017), other immigrants (e.g. Ruppenthal et al. 2005, Halcomb et al. 2007) or newcomers (Ogilvie et al. 2008). Even though combining asylum seekers with other groups gives insight into some details, such as linguistic issues, there is a lack of emphasis on asylum seekers' special and unique life situation as a vulnerable group.

2.4 Summary of the literature

Privacy is one key element in health care, including nursing, where patients' have the right to privacy. Respect of patients' privacy is part of clinical role of the nurses and good nursing practice, and is related to patients' satisfaction with care. Privacy is individually experienced, situationally dependent and involves an ongoing dialectic process with the surrounding world. In this study, the focus is in the cultural aspect of privacy, specifically from the perspective of Somali culture.

Somali's immigrate to new country for different reasons, and Somali asylum seekers and refugees form one part of Somali patients. Besides the common health problems of Somali patients, Somali asylum seekers and refugees suffer from various health problems due to pre- and post-settlement experiences, requiring health care services. Somali asylum seekers and refugees form a vulnerable group based on their experiences, which has to be emphasised in health care. In health care, Somali patients face several challenges related to relationship with the health care professionals, culture and language. The main solution to reduce linguistic challenges is the use of interpreters. The use of interpreters improves the quality of care, however, there are several studies indicating that the use of interpreter causes challenges faced by both patients and health care professionals. One of the main challenges has to do with the patient-nurse-relationship, which change into a more complex patient-nurse-interpreter-relationship. This causes for example questions of confidentiality and privacy.

The few studies done in the perspective of privacy of Somali patients, discuss privacy using its related concepts, such as trust. These studies focus mainly on reproductive and mental health care. Studies indicate, that cultural issues, such as stigmatisation and fear of being rejected by the community, have a big role in sharing information. Somali patients have also been reported not to trust interpreters and being unwilling to share information with them. When focusing on the privacy of Somali asylum seekers and refugees, and use of interpreters in health care, the database search didn't reveal any hits, which reveals a lack of knowledge on the privacy of Somali asylum seekers and refugees in health care.

When it comes to health research, the database search revealed a lack of knowledge on the factors related to the use of interpreters in health research with asylum seekers. Asylum seekers are usually combined with other immigrant groups, such as refugees, meaning that the special situation and special needs of asylum seekers related to their vulnerable situation are not emphasized. Research with asylum seekers usually requires an interpreter, which can impact the whole research process.

3 AIM, PURPOSE AND RESEARCH TASKS

The aim of this descriptive study was twofold. First, in the empirical part, the aim was to describe the content, importance and realisation of privacy of Somali asylum seekers and refugees, and the factors related to the use of interpreters in Finnish health care. Second, in the methodological part, the aim was to identify the factors related to the use of interpreters in health research.

The purpose of this study was, firstly, to obtain an understanding of privacy in the Somali culture and to improve the realisation of privacy, and secondly, to obtain an understanding of the use of interpreters required both in health care and in health research with Somali asylum seekers and refugees in Finnish health care.

The research tasks of the study were:

1. What is privacy for Somali patients in Finnish health care? (I)
 - 1.1 What is the content of privacy?
 - 1.2 What is the importance of privacy?
2. How is privacy realised and what are the factors related to the realisation of privacy in health care for Somali patients in Finnish health care? (II)
 - 2.1 How is privacy realised?
 - 2.2 What are the factors related to the realisation of privacy?
3. What are the factors related to the use of interpreters in Finnish health care? (III)
4. What are the factors related to the use of interpreters in health research with asylum seekers? (IV, Summary)

4 MATERIALS AND METHODS

This chapter describes the material and methods of this study. The study was conducted in two parts, including four sub-studies, which were conducted between 2008 and 2017. (Table 4.)

Table 4. Material and methods

| Sub-study, year | Research task | Setting | Sampling | Methods of data collection and data analysis | Article |
|------------------------------|--|--|----------------------------|--|---------------|
| Empirical part | | | | | |
| Sub-study 1 2011-2012 | What is privacy for Somali patients in Finnish health care? | Four reception centres | 18 Somali asylum seekers | Focus group interviews Inductive content analysis | I |
| Sub-study 2 2015-2016 | How is privacy realised and what are the factors related to the realisation of privacy in health care for Somali refugees? | Two health care stations, one immigration services office, one adult education institute | 29 Somali refugees | Questionnaire Deductive content analysis | II |
| Sub-study 3 2008 | What are the factors related to the use of interpreters in health care? | 8 health care stations of one health care centre | 8 Public health nurses | Individual interviews Inductive content analysis | III |
| Methodological part | | | | | |
| Sub-study 4 2015 and 2017 | What are the factors related to the use of interpreters in health research with asylum seekers? | Part 1: Medline, CINAHL, and Medic databases Part 2: Medline and CINAHL databases | 33 articles 17 articles | Literature review | IV Summary |

4.1 Data collection and analysis

Data for the study were collected using four different data collection methods: focus group interview (sub-study 1), questionnaire (sub-study 2), individual interviews (sub-study 3) and literature review (sub-study 4). All data were analysed by content analysis (Graneheim & Lundman 2004). (Table 4.)

4.1.1 Focus group interview and inductive content analysis

Data collection

Focus group interviews and inductive content analysis were used in sub-study 1 (table 4), aiming to describe the content and importance of privacy for Somali asylum seekers (I). Focus group interviews were chosen as data collecting method because they enable to derive a collective perspective and allow synthesis and validation of ideas and concepts in culturally and linguistically diverse groups (Halcomb et al. 2007) and because of the collective nature and strong oral background of the Somali culture (Lewis 2008). When planning the interviews, careful attention was given to the researchers' knowledge and skills, to practical preparation, and to the interpreter's competence, role and cultural background. Somali asylum seekers were seen both as individuals and members of a cultural and communal group.

The focus group interviews were conducted, with the support of an interpreter, in four different reception centres in Southern Finland in December 2011 and January 2012. The centres were chosen based on the highest number of Somali asylum seekers (a total of 28). The participants were selected using purposive sampling. Prior to data collection, oral and written information about the study was given to all 28 adult Somali asylum seekers one week before the interviews, with the help of reception centres workers with Somali background in each reception centre. A total of 18 Somali asylum seekers were willing to participate in the study, forming four focus groups, one in each reception centre. At the beginning of the interviews the same information was given to the participants by the researcher orally and in writing, with the help of an interpreter. All participants signed a written informed consent. In order to check the questions and timing, the first focus group interview served as a pilot. After the pilot, no changes were made, and the pilot group was included in the data.

The focus groups were divided by gender, except for one, in which the participants, male and female, wanted to participate in the same group. Besides the one mixed-gender group, there was one group of females and two groups of men. The focus group interviews were conducted in Finnish by the researcher and interpreted into Somali. The interpreter was female. The use of a male interpreter was considered; however, a decision was taken to use the same interpreter in all interviews for several reasons. Firstly, the use of the same interpreter in all the interviews increases the trustworthiness of the study (Wallin & Ahlström 2006, Squires 2009). Secondly, the interpreter had high-level

language and cultural knowledge of Somali and Finnish cultures, a degree in nursing and long working experience in both nursing and interpreting. Thirdly, none of the participants, including the male participants, had any problems with the gender or personality of the interpreter and the participants saw her as “a sister”. Before the interviews, the role of the interpreter was discussed, and the active interpretation method was chosen, including cultural explanation, not only translation word by word (Squires 2008).

In the beginning of the interviews, the correct term for “privacy” was discussed, since it varies in different dialects in the Somali language. Either the term “xad”, meaning limit, or the English word “privacy” was used. The discussion in the interviews was lively and everyone had the chance to speak. The interviews were audiotaped for analysis, but also in order to check the interpretation in situations where the lively discussion prevented simultaneous interpretation. The interviews lasted from 1 hour 22 minutes to 2 hours 23 minutes.

Data analysis

The data were analysed by inductive content analysis (Graneheim & Lundman 2004) by the researcher. First, the audiotaped focus group interviews were listened to, including some lively discussions that the interpretation could not keep up with, and the interpretations were checked. Both research tasks were analysed separately. Firstly, significant statements answering the research tasks were identified. Secondly, the statements were condensed twice: first, in order to form a description close to the text, hindering the explanations of the interpreter and emphasising the answers of the participants, and second, to form an understanding of the meaning. For example, the significant statement spoken by the interpreter “He said that if there absolutely wasn’t any other doctor than a male doctor and the baby was coming, he would accept a male doctor” was first condensed into “If there absolutely wasn’t any other doctor than a male doctor and the baby was coming, I would accept a male doctor” and then into “I would accept a male doctor for my wife in case of acute childbirth”. Thirdly, the condensed statements were combined into sub-themes according to the similarities, and further combined into themes. The analysis revealed a total of three themes with four sub-themes describing the content of privacy, and three themes for the importance of privacy. In the results, quotations from this data are used to clarify the results and the trustworthiness of the analysis. The participants of this study are marked based on the group number and gender (e.g. G1, female).

4.1.2 Questionnaire and deductive content analysis

Data collection

Questionnaire (Appendices 1 and 2) and deductive content analysis were used in sub-study 2 (table 4) aiming to describe the factors related to the realisation of privacy in health care for Somali refugees (II). The data collection was conducted in Southern Finland, in two health care stations, one immigration services office and one adult education institute in 2015–2016 with the help of two Somali research assistants. The participants were selected using purposive sampling, and all Somalis in the participating institutes who had been in Finland for a maximum of three years and had refugee status were given the opportunity to participate in the study. Prior to data collection, oral and written information was given to the participants in Somali language by the researcher with the help of Somali research assistant. The information emphasised the aim of the study and ethical issues, such as voluntariness and the study's independence of any health care or education services. A total of 37 Somali refugees reported their willingness to participate, but 8 of them had been in Finland for more than 3 years, so the total number of participants was 29.

The data were collected using a questionnaire including 13 background questions and two open-ended questions in Somali language. The questions and instructions for the open-ended questions were formed based on the results of sub-study 1, describing the content and importance of privacy for Somali asylum seekers. In the open-ended questions, the participants were asked to describe two situations of realisation of privacy in health care. Stories were chosen because Somali culture has a long history in storytelling (Lewis 2008) and it has been recognised to be a valuable data collection method (Palacios et al. 2015). The following instructions were given to the participants: 1: How would you describe a positive appointment with a nurse in the presence of an interpreter? Write down a situation where you and your privacy have been respected and/or you have not felt ashamed during or after the appointment. 2: How would you describe a negative appointment with a nurse in the presence of an interpreter? Write down a situation where you and your privacy have not been respected and/or you have felt ashamed during or after the appointment. In case of illiteracy, the participants had the possibility to fill the questionnaire with the help of Somali research assistant or the researcher. The questionnaire did not include personal details, such as names, to ensure the anonymity of the participants. The willingness to fill the questionnaire was considered as consent to participate in the study.

Data analysis

The data were analysed using deductive content analysis (Elo & Kyngäs 2008) by the researcher. First, the responses were translated into Finnish language. Then, the main themes for structured matrix were formed based on the categories in sub-study 3: factors related to health care professionals, interpreter and patient. In analysis, words, phrases or sentences describing factors related to the realisation of privacy were used as meaning units and coded into three main themes. Inside the main themes, subthemes and themes were created following the principles of inductive content analysis (Elo & Kyngäs 2008). Firstly, the meaning units were condensed, secondly, related meaning units were combined to form subthemes. Thirdly, the subthemes were further combined to form themes. The analysis revealed a total of seven themes with 16 sub-themes. In the results, quotations from the data are used to clarify the results and the trustworthiness of the analysis. The participants of this study are marked based on their given number of the questionnaire and gender (e.g. Q10, male).

4.1.3 Individual interviews and inductive content analysis

Data collection

Individual interviews and inductive content analysis were used in sub-study 3 (table 4), aiming to describe the factors related to the use of interpreter in health care (III). The interviews were conducted in eight health care stations of one health care centre with a total of 20 health care stations in 2008. The study place was chosen based on the large number of immigrants living in the area of the health care centre. The participants were selected by purposeful sampling from the email list of public health nurses responsible for immigrant issues. The list consisted of 20 nurses. The nurses were contacted with a letter including information about the study. Eight nurses were willing to participate in the study, all of them female. The participants had worked in health care stations on average eight years and they all had experience of immigrant patients and the use of interpreters.

The data were collected using individual interviews by the researcher. At the beginning of the interviews, information about the study was given orally. The interviews were guided by the following question: What factors have to be considered when using interpreters in primary health care of immigrants? The interviews lasted on average 60 minutes and were audiotaped and transcribed.

Data analysis

The data were analysed by inductive content analysis (Graneheim & Lundman 2004) by the researcher. First, the transcribed interviews were read through carefully in order to get an overall picture of the interviews. Second, the data were divided into meaning units: single word, sentences or thoughts, and the meaning units answering the research tasks were picked up and condensed. Third, the related meaning units were grouped together into subcategories. Based on the similarities of the subcategories, they were further combined into categories. The analysis revealed a total of three categories and nine subcategories. In the results quotations from the data are used to clarify the results and the trustworthiness of the analysis. The participants of this study are marked based on the number of the interview (e.g. I2).

4.1.4 Literature review

A literature review was conducted in the second, methodological part, including sub-study 4 (table 4), aiming to describe the factors related to health research with asylum seekers. The literature search was conducted in two parts. The first part was focused on the planning of focus group interviews with asylum seekers (IV). The database search was conducted in the Medline, CINAHL, and Medic databases. The following search terms were used: qualitative research or focus group; immigrant or asylum seekers or refugees or cultural group or ethnicity; interpreter. Articles with the following inclusion criteria were selected: Article discussed qualitative research methods and research in multicultural settings, published 2000-2017. After database search, a manual search was conducted using the reference list of selected articles. Out of 85 hits, a total of 33 articles were selected. The findings of this literature review are reported in article IV.

The second part focused on the use of interpreters in health research with asylum seekers. It was conducted to Medline and CINAHL databases, with the search terms interpreter and research method, which were combined together. The term asylum seeker was not included in the second part of the search, since including it limited the hits into one publication, which is part of this thesis. Articles with the following inclusion criteria were selected: Article discussed research methods and research in multicultural settings, published 2000-2017. After database search, a manual search was conducted using the reference list of selected articles. Out of 82 hits, a total of 17 were selected, which are congruent with the articles selected in the first literature review. The results of this literature review are reported in the result part of this summary.

In both literature reviews, the data were analysed using thematic synthesis. First, coding of the findings of primary studies was done; secondly, these codes were organised into related areas to construct descriptive themes. (Thomas & Harden 2008.)

4.2 Ethical considerations

This study was conducted according to Finnish legislation (Medical research act 488/1999) and ethical guidelines on research ethics (The National Advisory Board on Social Welfare and Health Care Ethics [ETENE] 2006, Finnish Advisory Board on Research Integrity [TENK] 2012, World Medical Association [WMA] Declaration of Helsinki 2013). Due to the vulnerable situation of Somali asylum seekers and refugees (European Commission Directorate-general for Research and Innovation 2017), careful attention was given to research ethics during the whole research process. In the following, ethical considerations concerning the required permissions and approvals and the ethical issues related to the data collection and data analysis are discussed.

Sub-studies 1, 2 and 3 (I, II, III) were granted ethical approval by the Ethical Committee of the University of Turku (13/2011, 9.5.2011, 27/2014, 4.6.2014). The permissions for data collection were obtained from all the participating organisations.

In data collection with Somali asylum seekers and refugees in sub-studies 1 and 2 (I, II), special attention was given to the vulnerable position of the participants. When recruiting asylum seekers for focus group interviews, direct contact between the researcher and asylum seekers is suggested, since it makes the research more visible and easier to understand for the participants (Ogilvie et al. 2008). However, in order to highlight the voluntariness and anonymity, the researcher first contacted a cultural broker, reception centre worker, nurses, teachers or other people familiar to the participants, who contacted the participants. The researcher contacted the participants only after they had agreed to participate. All information of the study was given both in writing in the participants' language (Somali) and orally, either directly or using an interpreter. The study information included description of the study and its practical issues, anonymity of the participants and confidentiality issues. The information highlighted that participating or not participating in the research had no impact on the health care or asylum application procedure of the participants, and the data collected would only be used for the research and be seen only by the researcher and her supervisors. The cultural differences in decision-making were

acknowledged (Halkoaho et al. 2016). The participants were informed about the study at least one week before the data collection. This enabled the participants not only to reflect on their willingness to participate, but also if desired, to discuss the matter with their family or other significant people if needed.

The term “Somali” was used to refer to all people coming from Somalia or Somaliland, including the members of minority groups of Somalia. Some members of the minority groups took part in the study, all participants were treated with respect, and no discrimination was observed during the data collections.

In sub-study 1 (I), the participants signed a written informed consent form, which was discussed prior to the interviews. Emphasis was given to participants’ awareness of what they were signing. The informed consent form was written in Somali language and it was read through by the interpreter in case of illiterate participants. The participants had the possibility to ask about the form. All the participants were willing and able to sign the form, so no alternative method was needed (Ruiz-Casares 2014, Halkoaho et al. 2016). In sub-study 2 (II), the filling of the questionnaire was considered consent for participation. No names or other personal identification information were asked. In all data collections, the participants had the chance to interrupt the participation any time they wanted.

In sub-study 3 (III), the data were collected with individual interviews. Before the interviews, all public health nurses were sent written information about the study by email. The information included information about the study, practical issues and ethical issues, such as voluntariness (including the right to withdraw at any time) and confidentiality. At the beginning of the interviews, the same information was given orally.

There are ethical issues related to the use of interpreters in research (Wallin & Ahlström 2006). Before the data collections with Somali participants (I, II), the role of the interpreter was discussed with the participants, emphasising the confidentiality and neutrality of the interpreter. A female interpreter was used in all data collections. The use of a male interpreter was considered; however, the use of the same interpreter increases the trustworthiness of the research, and the qualifications of the interpreter in both interpretation and nursing related issues were considered to be important for the wholeness of the study (Wallin & Ahlström 2006, Squires 2009). None of the participants had any problems with the personality or gender of the interpreter.

5 RESULTS

The main results of this study are reported in three parts. The first part describes the content, importance (I) and realisation (II) of privacy from the perspective of Somali asylum seekers (I) and refugees (II). The second part describes the factors related to the use of interpreters in health care (III), and the third part describes the factors related to the use of interpreters in health research with asylum seekers (IV).

5.1 Privacy for Somali asylum seekers and refugees in Finnish health care

The aims of the first and second sub-studies were to describe the concept of privacy in the Somali culture among Somali asylum seekers, and the factors related to the realisation of privacy in health care for Somali refugees in Finnish health care. (I, II)

5.1.1 Content of privacy (I)

Based on the analysis, the content of privacy for Somali asylum seekers was divided into three themes: visual privacy, physical privacy and informational privacy. The themes were further divided into sub-themes revealing with whom the content of privacy was shared: 1. No-one, 2. Family members, 3. Person of the same gender, 4. Health care professionals and interpreters used in health care. (I)

Visual privacy referred to the viewing of someone's body. According to the Somali asylum seekers, the body could be revealed to family members, persons of the same gender and health care professionals and interpreters, with some restrictions. The naked body was seen to be part of sexuality, and sexuality was strictly limited to between husband and wife. Besides spouses, the naked body could be revealed in the presence of persons of the same gender. *"When I am with my husband, I can take my clothes off, but not if I am with some other male."* (G1, female) (I)

In health care, revealing one's body was acceptable when justified, regardless of the gender of the health care professional. However, the interpreter was not considered to be part of the health care team, and the gender and ethnic background of the interpreter was important. In the presence of an interpreter

from Somali culture, the cultural norms were strong: the body could be revealed only if the interpreter was of the same gender. Some of the participants did not want to reveal their body at all in the presence of the interpreter, since he/she was seen as an outsider. *“I don’t want to take off my clothes in front of a male interpreter, especially if he is Somali.”* (G1, female) (I)

Physical privacy referred to physical contact, to who could touch someone. It was shared with family members, persons of the same gender and health care professionals. Gender played a big role in physical privacy, which was related to sexuality. Gender was seen to be more important than family relations. Touching the other gender was appropriate only in the case of taking care of children or physical contact between spouses. *“No, I don’t let other men than my husband touch me.”* (G1, female) (I)

Especially in health care, the gender of the health care professional was considered to be important in the case of touching. In some cases, gender was not important, but in those cases the touching needed to be clearly explained. In gynaecological health issues, the gender of the health care professionals was extremely important both for Somali men and women. Only in case of emergency, such as childbirth, if there was absolutely no choice, could the health care professional be of the opposite gender. However, some participants described that health care professionals were considered *“just doing their job. It is not related to sexuality. They are there to help you.”* (G3, male) (I)

Informational privacy referred to information, which was not shared with others. Some information was shared with no one, some between family members, some with persons of the same gender, and some with health care professionals and interpreters. (I)

The most private information was not shared with anyone. This included issues strictly against Somali culture or religious rules, such as sexual relationship outside marriage or rape. Not sharing these issues was justified to protect not only the respect and dignity of the individual, but mainly the respect and dignity of the family or clan. *“It can be something bad you did, and you don’t want anyone to know, or people start talking about you.... Your community will reject you.”* (G4, male) (I)

Information shared mainly inside the family included issues related to sexuality and mental health problems. These issues had to be shared as little as possible, in a controlled manner, and mainly in the case of a problem. Sharing information with people of the same gender was based on the understanding within genders.

However, some men preferred sharing information with women rather than men, because they felt women had more empathy and compassion than men. (I)

In health care, sharing information was not a problem. Somali culture, religion and society justify sharing health-related information with health care professionals, even if it is otherwise against cultural or religious norms. Confidence towards health care was considered strong even though it was sometimes compulsory in order to get treatment. Somali asylum seekers were aware of the Finnish legislation on patients' rights, which promoted their trust towards health care professionals. Interpreters, on the other hand, were mainly seen as representatives of Somali culture, not a member of health care, and they were not trusted; especially their confidentiality was questioned. *"I just don't trust the interpreter. The interpreter knows all the Somalis here, and knows a lot about me."* (G1, male) (I)

5.1.2 Importance of privacy (I)

The importance of privacy referred to the reason why privacy is maintained and why Somali people make choices regarding their own privacy. It was divided into three themes: respect, dignity and freedom. (I)

Respect. Privacy was seen to be a way of respecting religion, culture and community. It was also seen to be a way of being respected by the community. (I)

Respect for religion referred to Islam and its norms on what should be kept private. In order to be a good Muslim, to show respect for Islam, the norms of privacy of Islam were obeyed. For example, by using the veil Somali woman could show her respect for Islam and protect her visual privacy as guided by Islam. Respect for culture and community referred to Somali culture and its clans. In Somali culture, different clans have different sub-cultures, and protecting one's privacy according to the clans norm was a way of respecting one's culture and community. Being respected by the community was seen to be one of the main issues in privacy. Maintaining privacy meant "keeping one's face" in the community. The loss of privacy would mean the loss of respect of the community. (I)

Dignity. Privacy was seen to be a way of protecting dignity of the individual, family and the community. It was discussed through the feeling of shame, which occurs if someone loses his/her dignity. The loss of individuals' dignity and feeling of shame extended to the family and community, which made the

protection of individuals' privacy extremely important. In two groups a story with similar content was told about a pregnancy outside of marriage. To protect the families and community from shame, the families "solved the problem" by marrying the youngsters. (I)

Dignity and the feeling of shame were mentioned several times when discussing health care and the use of interpreters. The presence of an interpreter with Somali background was seen to increase the loss of dignity and the feeling of shame, whereas telephone interpreters or interpreters from other cultures were seen to enable disclosure of privacy which would not be culturally appropriate in the Somali culture. "*I prefer telephone interpreters, they don't see me*" (G2, female) (I)

Freedom. Freedom referred to individuals' choice to show, talk or share personal things with others. Freedom was guided by religion and culture and was seen to be related to the society they found themselves in. The change from Somali society to Finnish society both increased and decreased individuals' choice for privacy. It was increased because cultural taboos and forbidden subjects could be more freely discussed in Finnish culture than in Somali culture. However, the change of culture also decreased the freedom, especially in health care. Even though the change of society enabled the participants to speak more freely, it also forced them to do things they did not want to do since the new culture understood privacy in a way that differed from theirs. The participants felt they were forced to share private information about traumatic events in order to have arguments in support of the asylum application and to let health care professionals of the opposite gender touch them in order to get treatment. (I)

All groups discussed childbirth as an example of freedom. In Somalia, it was traditionally taken care of by women, while the men were left outside. In Finland, Somali men could attend childbirth. Some of the participants felt they were forced to act against their own values; however, some of them felt it to be a relief and considered it a freedom. (I)

5.1.3 Realisation of privacy in Finnish health care (II)

Based on the analysis, the factors related to the realisation of privacy, were divided into three main themes: factors related to the patient, factors related to the health care professional and factors related to the interpreter.

The questionnaire included three questions related to the realisation of privacy based on the content of privacy: visual, physical and informational. Of a total of

29 participants, 13 had experiences of violation of their visual privacy, 14 participants had experiences of violation of their physical privacy, and 17 had experienced violation of their informational privacy. (Table 5.) Eleven participants did not have any experiences on violation of privacy, while 11 participants had experienced violation of all three contents of privacy. (II)

Table 5. Violation of different contents of privacy (n=29)

| | Violation of visual privacy | Violation of physical privacy | Violation of informational privacy |
|-----------|-----------------------------|-------------------------------|------------------------------------|
| Yes n (%) | 13 (44.8) | 14 (48.3) | 17 (58.6) |
| No n (%) | 16 (55.2) | 15 (51.7) | 12 (41.4) |

Factors related to the patient included autonomy and satisfaction with the care (II).

According to the Somali refugees, autonomy included self-determination and possibility to act according to one's own culture. Privacy was realised when the patient's self-determination was respected. It was described as a possibility to choose the gender of the interpreter or not feeling forced to share private information or reveal one's body. A male participant wrote an account of a situation where he had a health problem and felt forced to act against his will "...I didn't want to show my penis to the nurse, but I had to". (Q7, male) (II)

The possibility to act according to one's own culture improved the realisation of privacy. Respecting the cultural norms of Somali culture, such as not talking about certain issues or revealing the body, was considered important in health care. Cultural differences between Finnish and Somali cultures were acknowledged. Participants' stories revealed knowledge about the Finnish culture; however, it did not diminish their need to act according to the Somali culture. "*I don't want to show my private parts to the interpreter, even if she is female. I know it can be done in Finnish culture, but not in my culture. It makes me ashamed.*" (Q5, female) (II)

Satisfaction with the care included receiving good treatment, trusting the health care professional and the interpreter, and knowledge and understanding of treatment. Good treatment improved the realisation of privacy for Somali refugees, and it was mentioned in several stories. Some stories explained good treatment to include getting an appointment quickly with health care professionals, and it was considered to improve the realisation of privacy. Trusting health care professionals and interpreters improved realisation of

privacy when the participant could trust both. Trusting health care professionals was mentioned in several stories describing good realisation of privacy: *“I get the appointment (with health care) when I need it, and I don’t consider that there are any problems in my care. Usually I don’t have an interpreter, but sometimes the interpreter might be present. I haven’t faced any violation of privacy. I like to talk about my health issues, and I trust the nurse.”* (Q3, male) (II)

Knowledge and understanding of treatment was seen to improve the realisation of privacy. Participants described situations where they were asked to do something (e.g. take off their clothes), and they did not understand why. They described how no one explained to them what to do or why. Anything related to health could be shared, but participants often did not understand the relation between the issue they were supposed to share and health. One participant wrote about a situation during childbirth. There were a lot of people present, but she was not aware why these people were there. She presumed they were medical students wanting to learn about female circumcision. She described feeling like *“a laboratory animal”* (Q23 female). In stories related to good realisation of privacy, participants told about nurses who explained all the time why certain things have to be done. (II)

Factors related to the health care professional included personal and professional factors (II). Personal factors including the gender and personal characteristics of the health care professional improved the realisation of privacy, if the gender was the same as the participant’s. Both men and women described a good situation in health care when the nurse or doctor had the same gender as themselves. There were also stories describing indifference to gender, mainly related to urgent situations or childbirth. *“When I was giving birth, I was asked if a male doctor could participate. I said yes, all I wanted was for my baby to be born healthy and safely. Everybody treated me well.”* (Q28, female) Besides gender, the personal characteristics of the health care professional were considered to improve privacy when the professional was respectful, kind, polite and helpful. (II)

Professional factors of health care professionals included professional behaviour, ability to focus on health issues and knowledge and understanding of Somali culture. Professional behaviour and ability to focus on the health care issues improved the realisation of privacy. Professional behaviour was seen to include good co-operation, asking the patient’s opinion and not forcing the patient to do anything, and informing the patient. According to the participants, health care professionals were not able to focus on health issues in situations where the nurse

was asking questions or touched body parts that were not related to participant's health issue, or the participants did not understand the connection between the behaviour and their health issue. In those situations, privacy was not realised. *"Sometimes the nurse asks questions not related to my health. I don't know why she is doing that."* (Q29, female) (II)

Knowledge and understanding of Somali culture improved the realisation of privacy. It helped the nurse or doctor to avoid inappropriate questions, inquiries or actions. One female participant described a situation where she did not have to reveal her head, but only her ear. She felt her privacy was realised since the nurse did not ask her to reveal her head. Another participant was surprised how well her nurse knew and respected the Somali culture and acted according to the cultural norms. (II)

Factors related to the interpreter included presence, personal factors and professional factors (II). The presence of the interpreter decreased the realisation of privacy. Participants wrote about situations where they did not want the interpreter to see or hear private issues, such as issues related to sexuality. *"I don't want the interpreter to be present when the nurse or doctor is examining me"* (Q27, male) The presence of the interpreter might silence the patient or hamper the patient from consenting to treatment, as one participant wrote: *"I'd rather not have any treatment at all than tell my issues to the interpreter"* (Q25, male) (II)

Personal factors included the gender of the interpreter and cultural factors. In order to improve the realisation of privacy, the interpreter had to be of the same gender as the participant. One male participant explained that usually the nurse is female, and if the interpreter is also female, he does not feel comfortable. The cultural background of the interpreter improved the realisation of privacy from the perspective of cultural knowledge. Somali interpreters were appreciated because of their cultural knowledge. However, the participants were worried about cultural norms and small communities. *"The interpreter knows a lot of things about me, also things that are bad in our culture. And he/she knows a lot of Somali people. I feel distressed."* (Q2, female) (II)

Professional factors of the interpreter included professional behaviour and professional competence. Disrespectful behaviour and lack of competence were related to bad realisation of privacy. Patients described situations where the interpreter asked disrespectful questions, expressed their own opinions or talked in a loud voice so outsiders could hear the conversation. They also wrote about situations where they suspected that the interpreter was interpreting wrongly.

“The interpreter asked disrespectful questions, and I’m sure he/she interpreted them wrong! I refused to answer. The interpreter said that if I don’t answer, I won’t get any treatment.” (Q25, male) (II)

5.2 Use of interpreters in health care (III)

The aim of the third sub-study was to describe nurses’ perceptions of the factors related to the use of interpreters in Finnish health care. Based on the analysis, the factors were divided into three categories: factors related with the patient and their culture, factors related with the nurse and the health care organisation, and factors related with the interpreter. (III)

Factors related with the patient and the culture included patients’ perception of the interpreter, patients’ privacy and patients’ desires concerning the interpreter. Patients’ perceptions of the interpreter that nurses had encountered varied from the interpreter being a common helper or friend to a total stranger. The nurses had noticed that some patients wanted the interpreter to help them not only health care related problems but with all kinds of matters, such as translating documents or escorting patients to various places. The nurses mentioned that the interpreter was seen as a friend, especially in collective cultures. A close relationship between the patient and the interpreter was seen to interfere with the professional relationship between the nurse and the patient, and made nurses feel outsiders. However, if the interpreter was seen as a stranger, it harmed the nursing relationship by hindering communication. *“I get the feeling that the patient is not telling me everything. Then the next time, when the interpreter is not there, the patient tries to tell me something. (I6) (III)*

Patients’ privacy was a concern for all nurses. The confidentiality of the interpreters was sometimes questioned, in spite of awareness of their professional rules and code of ethics. Mistrust towards the interpreter was the most common reason why patients did not want to use interpreters. The use of the same interpreter with the same patients during all appointments was seen as way to increase the privacy of patients. *“I wish the interpreter could be the same. They (patient and interpreter) could build trust between them.” (I3) (III)*

Patients’ desires concerning the interpreter were faced by all nurses. The most common desires were a specific person or family member, or a specific gender. The gender of the interpreter was seen to be connected to cultures where contact between the genders is limited, such as Somali culture. Patients’ desires were observed and realised if possible. However, family members were not used as

interpreters since it was seen as a major ethical issue, as it could create problems of privacy and cause role changes inside the family by making the child take responsibility for his/her parents. (III)

Factors related with the nurse and health care organisation included planning the appointment, realisation of the appointment and education of nurses. (III) Planning of the appointment included the decision to use an interpreter, ordering the interpreter, the availability of the interpreter and the planning of the content and timing of the appointment. The decision to use an interpreter was made based on the health care centres' guidelines. Beside the need of an interpreter, nurses had to think about the costs of the use of interpreters. However, if the decision of whether to use an interpreter or not was mainly based on costs, not on need, it would put patients in unequal position. As one nurse expressed: "*My main point is the patient, not the guideline.*" (I6). The ordering and availability of interpreters was considered challenging and time-consuming. Access to the interpreter service by phone was considered difficult, which increased the nurses' workload, and poor availability of interpreters posed challenges in urgent situations or if the nurse wanted to have the same interpreter in recurring appointments. Since using an interpreter was expensive and required almost double the time compared to appointments without an interpreter, the content of the appointment was planned carefully and the patients were informed as to which topics would be discussed each time. (III)

Realisation of the appointment included the physical arrangements and communication. In order to increase equality between the patient, nurse and interpreter, and to emphasize the neutral role of the interpreter, a triangle form of sitting was prioritised. In communication, nurses directed their speech directly to the patient, through the interpreter, to emphasise the relationship between the patient and nurse. "*I focus on the patient. I look at the patient, I speak to the patient.*" (I4). The communication style was clear, and the use of standard language, avoiding medical terminology and jokes, was seen as important. (III)

Education of the nurses on how to work with interpreters was insufficient. The use of interpreter was learned through experience; however, formal education was seen to increase the awareness and important skills on the use of interpreters. Lack of education was seen to be one reason why some nurses did not want to use interpreters or even to have immigrant patients. (III)

Factors related with the interpreter included professional knowledge, professional role and personal characteristics. (III) Professional knowledge, including broad linguistic knowledge, cultural understanding and ethical

background, was seen to be a fundamental requirement of the interpreter. The interpreter was expected to have strong language skills and an understanding of both cultures involved in the interpretation. In ethical background, the nurses emphasised neutrality, confidentiality and respect for the patient and nurse. (III)

The professional role of the interpreter was seen in terms of the interpretation method. The interpreter was seen either as a translation machine or as a cultural bridge. When the interpreter was considered to be a translation machine, he/she was expected to translate the spoken message word by word. This interpretation method was considered to be professional and trustworthy. When the interpreter was considered to be a cultural bridge, he/she was expected to explain the cultural differences besides the interpretation. This method was seen to have a positive effect on the atmosphere; however, it was considered to be less trustworthy. "It is complicated. Sometimes it is better to get only the interpretation, and sometimes the interpreter is worth their weight in gold when he/she explains the cultural differences." (I2). The trustworthiness of the interpretation was based on the length, rhythm and pauses during the interpretation, and their relevance to Finnish language. It was the only way the nurses could evaluate the trustworthiness and the language skills of the interpreter. (III)

The personal characteristics of the interpreter had either a positive or negative effect on the relationship between the nurse, patient and the interpreter. The positive characteristics that had a positive effect on the relationship were empathy, delicacy, objectivity, sensitiveness, kindness and the ability to put oneself in the patient's situation. The negative characteristics that had a negative effect on the relationship were hot temper, lack of expressions, nervousness, monotony or stiffness. Despite the negative effect on the relationship, some of the negative characteristics, such as lack of expressions and stiffness, were seen as part of professionalism. (III)

5.3 Use of interpreters in health research with asylum seekers (IV)

The aim of the methodological part including sub-study 4, was to describe the factors related to the use of interpreters in health research with asylum seekers. Based on the analysis, the factors were divided into planning and conducting the research with asylum seekers.

The planning of research with asylum seekers and interpreters included acknowledging asylum seekers' immigration status, choosing the research

methods, recruiting asylum seekers for health research and choosing an interpreter.

Acknowledging asylum seekers' immigration status

Acknowledging asylum seekers' immigration status and their pre-settlement experiences is required in research with asylum seekers. The researcher needs to understand the cultural, historical, political and societal background of the participants. (Ogilvie et al. 2008.) Asylum seekers are in a vulnerable position because of their pre-settlement experiences. Those experiences can affect the participants' willingness to take part in health research, especially when conducted with the use of interpreters. Interpreters are usually used in narrative research methods; this might pose a risk of reactivating distress related to pre-settlement traumas and increase disempowerment and isolation (De Haene et al. 2010).

Based on their previous experiences of government and authorities in their own country, asylum seekers might be reluctant to share their migration history with strangers (Ruppenthal et al. 2005) and may feel distrust as to how the information will be used (Ogilvie et al. 2008). Even though the confidentiality of the researcher and the interpreter can be guaranteed, a discussion about the confidentiality between the other participants of group and the voluntariness of sharing private information during the interview should be held in the beginning of the interview. The level of participation can be affected by the assumption, that the data are collected only for professional interests, providing little value for the community under study (Ruppenthal et al. 2005), or that participating is related to additional services (Ogilvie et al. 2008) or will influence the asylum application procedure.

Choosing the research methods

Research methods including face-to-face interviews are suggested in research with newcomer immigrants, such as asylum seekers (Ogilvie et al. 2008). Narrative methods are suggested when the participants come from a collective culture (Halcomb et al. 2007), have a strong oral background or low literacy rate (Birks et al. 2007, Halcomb et al. 2007). Group-based methods, such as focus groups, are based on the social-psychological concept of group dynamics; however, it is based on Western traditions and its cultural aspects have only recently been recognised. (Carey 2016.) Group dynamics and the level of disclosure of the participants in focus groups can be affected by the cultural

norms of behaviour (Birks et al. 2007, Halcomb et al. 2007) and tensions in the country of origin (Ogilvie et al. 2008).

Sample size is dependent on research design; however, the special position of asylum seekers has to be acknowledged. The constant change in the asylum seeker population might cause challenges in obtaining an adequate number of research participants. The sample size of research participants may change at the last minute due to the risk of deportation or relocation (Ogilvie et al. 2008), different understanding of the concept of time or priorities in different cultures (Birks et al. 2007), and challenges with child care or other practical issues which may prevent participants from participating (Ruppenthal et al. 2005).

Recruiting asylum seekers

When recruiting asylum seekers for health research, an interpreter is usually needed to facilitate the communication between the researcher and participants. Direct contact between the researcher and asylum seekers is suggested for discussion on the expectations and wishes for the interview on the part of both the asylum seekers and the researcher (Ogilvie et al. 2008). Co-operation with reception centres or help from religious leaders or other links to the ethnic community (Ruppenthal et al. 2005) enables a direct approach for recruitment. In recruitment, the role of the interpreter is twofold: transferring the message, and acting as a cultural broker, explaining cultural aspects (e.g. fear of stigmatisation). Letters, posters or other indirect methods can be used to support the direct approach (Ogilvie et al. 2008); however, the literacy rate of the asylum seekers has to be acknowledged. All written material is usually translated due to asylum seekers' varying linguistic backgrounds (Ogilvie et al. 2008, Chen & Boore 2009). In translation, special attention has to be paid to dialects of the language in question (Ogilvie et al. 2008). The use of other methods, such as visual aids or multimedia, is also suggested (Ruiz-Casares 2014).

When it comes to decision-making and informed consent, the Western tradition focuses on the individual and his/her freedom of choice. The life situation and cultural norms of asylum seekers might be in conflict with Western norms, and individual freedom of choice can even be harmful for the participant or his/her community (Birks et al. 2007, Halkoaho et al. 2016). In some cultures the decision-making of individuals (such as women making decisions without permission from their husbands) might put the individual in danger within the family or community (Ruiz-Casares 2014). When it comes to the written informed consent, alternative forms should be considered (Halkoaho et al. 2016).

Asylum seekers may be reluctant to sign any paper, including the informed consent form, because of their cultural or pre-settlement experiences. Signing a paper may be viewed with suspicion. It can be associated with getting in conflict with the authorities (Ruiz-Casares 2014) or having an impact on their asylum application (Halkoaho et al. 2016).

Choosing an interpreter

When choosing the interpreter, the competence and cultural background of the interpreter are important. The interpreter's competence in both languages is essential for the cultural validity of the research, which is why the use of professional interpreters is recommended (Ogilvie et al. 2008, Squires 2008). The language competence can be divided into four levels: grammatical competence, discourse competence, sociolinguistic competence and strategic competence. For research purposes, the interpreter should possess at least the level of sociolinguistic competence. (Squires 2008.) Besides language competence, the interpreter should possess competence in the research field (Kapborg & Berterö 2002).

The cultural background of the interpreter and the recognition of the complexity of cultural aspects is essential when planning research with interpreters (Ogilvie et al. 2008, Plumridge et al. 2012). Even if the cultural background of the interpreter and the participants is usually the same, their cultural beliefs may be shaped by the time of immigration and integration into the new culture (Lynam et al. 2007), whereas asylum seekers might still strongly represent the culture of their country of origin (Halcomb et al. 2007). A shared cultural background, nationality or ethnicity with tensions originating from the country of origin can be a barrier for the research process, causing lack of trust towards the interpreter and hindering the sharing of information, thoughts and insights (Ogilvie et al. 2008). The class and position of the interpreter in the community has to be acknowledged since ethnic communities are usually small and tight-knit (Plumridge et al. 2012).

Factors related to conducting the research with asylum seekers include communication through the interpreter, creating a respectful and trustful environment and recognition of cultural aspects

Communication through the interpreter

Communication through the interpreter, cultural aspects and creating a respectful and trustful environment in multicultural settings are essential when conducting

research with asylum seekers and interpreters (Birks et al. 2007, Ogilvie et al. 2008). Communication through the interpreter requires using non-complicated language. The use of slang phrases, colloquialisms or complicated sentences increases the risk of misinterpretations and decreases the conceptual equivalence. (Squires 2008.)

In communication, the role of the interpreter is important for the trustworthiness of the research (Pitchforth & van Teijlingen 2005, Wallin & Ahlström 2006, Ogilvie et al. 2008, Squires 2008, Squires 2009, Plumridge et al. 2012) and for establishing a positive relationship between the parties involved in the research (Ogilvie et al. 2008, Plumridge et al. 2012). These two aspects are often seen to be in conflict when discussing the role of the interpreter from the viewpoint of active and passive interpretation methods. The trustworthiness is increased by using a passive interpretation method where the interpreter only interprets the spoken message (Squires 2008). An active interpretation method, where the interpreters also clarifies cultural concepts or phrases to the researcher and participants, promotes a trusting relationship between the three parties and improves the flow of conversation (Plumridge et al. 2012). Both methods have also disadvantages: the passive method has been criticised for having a negative effect on research (Pitchforth & van Teijlingen 2005, Ogilvie et al. 2008) by creating tension in the interview, by reducing the focus on the participants and by restricting the flow of conversation, while in the active method the interpreter may only summarise the conversation to the researcher, which may decrease the trustworthiness of the research as the interview is also guided by the interpreter, not exclusively by the researcher (Pitchforth & van Teijlingen 2005). Acknowledging the advantages and disadvantages of both methods supports the researcher in choosing the most suitable method for the interview.

Creating a respectful and trustful environment

Creating a respectful and trustful environment is essential for the rigour of the study (Im et al. 2004). Asylum seekers need to feel safe (Ogilvie et al. 2008) and understand the role of the researcher and interpreter (Im et al. 2004). The participants have to be fully informed about the aims and focus of the research, their role and the expectations during the data collection. Otherwise, there is a risk that the participants will answer the questions in a way they think the researcher wants them to answer in order to please the researcher. (Birks et al. 2007.) Asylum seekers might see the researcher as an authority (Im et al. 2004), which can lead to mistrust and fear of disclosure during the interview. The same interpreter might also have been interpreting with authorities, such as

immigration authorities, which might increase the mistrust. Creation of a respectful and trustful environment requires reflection of the researcher's position towards the participants (Ogilvie et al. 2008), flexibility in time (Im et al. 2004) and flexibility in the use of a strict protocol during the interview (Birks et al. 2007).

Recognition of cultural aspects

Cultural aspects might silence the participants because of cultural norms on discussing sensitive issues, especially with the presence of the interpreter. Careful monitoring of verbal and non-verbal communication of the participants helps the researcher to recognise and overcome possible challenges. Culturally different styles of communicating might affect the length of data collection. In cultures with a strong history of storytelling, the discussions may be time-consuming. (Halcomb et al. 2007.) The length of the discussion should not be limited before the data collection; the length should be flexible, allowing enough time for discussion. Cultural or religious ceremonies or praying can also prolong the data collection (Ruppenthal et al. 2005).

5.4 Summary of the results

In Somali culture, privacy is emphasised by the collective elements of culture. Privacy is seen important, because it is a way of respecting religion, culture and community, and it protects the dignity of the individual but mainly the dignity of the family and community. The individual's freedom to share private issues is guided by religion and culture. Depending on the content of privacy, privacy can be shared with no one, family members, persons of the same gender or health care professionals and interpreters in health care. In health care, everything can be shared with health care professionals; however, not with interpreters. Interpreter, usually from Somali culture, are not considered to be part of health care team.

The confidentiality of the interpreters was questioned by Somali asylum seekers, Somali refugees and nurses. They all feared, that the presence of the interpreter might silence the patient. Both Somali participants and nurses desired to have the same interpreter in the encounters, in order to create a trusting relationship between the patient, health care professional and interpreter. However, the participants indicated that they don't usually have the same interpreter.

In visual and physical privacy, gender was seen very important, both for Somali women and men. Being seen or touched by the opposite gender was considered confusing, embarrassing, disrespecting and shameful. In health care the violation of visual and physical privacy was approved, when it was justified, and understood to be related to health. Health care professionals' knowledge and understanding of Somali culture, was seen to help the mutual understanding on privacy.

In the methodological part, several factors related to the use of interpreter in health research were identified in the literature. The factors related to the planning of research were acknowledgement of asylum seekers' immigration status, choosing the research methods, recruiting asylum seekers and choosing the interpreter. The factors related to the conduct of the research included communication through the interpreter, creating a respectful and trustful environment, and recognition of cultural aspects.

6 DISCUSSION

The discussion chapter discusses the results and trustworthiness of the study. In addition, the implications for nurse education, nursing practice and further research are presented.

6.1 Discussion of the results

The results are discussed based on the two study parts. First the results of the empirical part are discussed by discussing privacy for Somali asylum seekers and refugees in Finnish health care. Secondly, the results of the methodological part are discussed.

6.1.1 *Privacy for Somali asylum seekers and refugees in Finnish health care*

Privacy in Somali culture

The first main finding of the study was the description of the importance, content and realisation of privacy, which were guided by Somali culture and religion. The term “privacy” varies in different dialects in the Somali language, which can explain why earlier studies conducted with Somali patients, discuss privacy within its related concepts, such as trust, confidentiality and secrecy (eg. Carroll et al. 2007a). In this study, the Somali term “xad” or English term “privacy” was chosen to be used in the data collections, in order to have a mutual understanding.

In order to understand privacy in Somali culture, the importance and its relation to the collective elements of the culture and the religion has to be recognised. The Somali culture is a collective culture where the patriarchal lineage is important and the needs of the family or community are more important than the needs of individual, this reflects also to the importance and content of privacy. According to this study, privacy was considered to be a way to respect religion, culture and community, and protecting dignity. This is a big difference compared to Western cultures where the emphasis of privacy is on the individual (Beauchamp & Childress 2009). The loss of privacy might lead to feelings of shame, not only for the individual, but also the family, and in the worse case, to rejection from the community; for Somali patients, protecting privacy is thus more than just protecting the individual, it is protecting the whole community and its dignity. These differences between individual and collective cultures

might explain the challenges Somali patients face in health care, and there is a need for mutual understanding on cultural differences regarding privacy in health care.

Asylum seekers and refugees have both immigrated to new country, although their post-settlement experiences are different. One post-settlement experience is new social network and status. Laufer & Wolfe (1977) argued, that changes in social life affect the perception of privacy. According to the results, Somali asylum seekers experienced, that their freedom of privacy in health care had increased in the new country and culture. Somali asylum seekers felt more free to share private information with health care professionals from another culture. Similar results have been reported earlier (Verran et al. 2015). However, the participants in this study felt forced to act against their own expectations of privacy for two reasons. First, in order to prove their eligibility for international protection, asylum seekers often need a medical evaluation (Lustig et al. 2008, Scruggs et al. 2016), which requires sharing their traumatic experiences and agreeing to physical examinations. Second, in order to get any treatment, the participants felt forced to comply with examinations and discussions regardless of the presence or gender of the interpreter and the gender of the health care professional. Even though some level of disclosure of privacy is accepted in health care (Stone-Romero et al. 2003, Woogara 2005), and might be essential for the eligibility for international protection, the vulnerable position of the patients may affect on their ability to control their privacy, which might lead to breach of privacy (McParland et al. 2000b) and has to be acknowledged.

Content of privacy

The content of privacy was divided in visual, physical and informational privacy. These contents were either shared with no-one, family-members, person of the same gender and/or with health care professionals. The most private contents, which were not shared with anyone, had many of the same elements, than the concept of secrecy (eg. Pinch 2000). They were strictly controlled, and their disclosure posed a risk of stigmatisation within the community

When it comes to visual and physical privacy in the Somali culture, gender was seen as very important for both women and men. Earlier studies mentioning privacy of Somali patients, have been done from the perspective of reproductive health care, and are mainly focused on female patients (e.g. Carroll et al. 2007b, Degni et al. 2012, Hill et al. 2012, Byrskog et al. 2014, Kingori et al. 2016). Compared to previous studies, this study revealed that visual and physical

privacy is not only important for female, but also for male patients. Male participants had experienced violation of their privacy, and had experienced the same kind of feelings as women. Being seen or touched by the opposite gender in health care was considered confusing, embarrassing, shameful and disrespecting one's privacy. Sexuality and everything related to it, such as reproductive health care, seem to be one of the most private things in the Somali culture for men and women alike.

The findings showed that according to Somali culture, health-related information can be shared with health care professionals. Previous studies have been controversial on the willingness of Somali patients to share information about their illness with health care professionals (Dahal et al. 2014, Piwowarczyk et al. 2014, Wolf et al. 2016) and discuss the importance of family when sharing private health information.

Realisation of privacy

When it comes to the realisation of privacy, over half of the participants had experienced some kind of violation of privacy while one third had no experiences of any kind of violation of privacy. Even though these results can't be generalised, earlier studies indicate to be similar (e.g. Nayeri & Aghajani 2010). In this study, purposive sampling was used to collect experiences of privacy in health care, and this might have resulted in selecting participants with experiences of violation of privacy. On the other hand, this is the first study where realisation of Somali refugees' privacy has been studied, and studies done with different cultures, immigrant groups or nursing environments cannot be directly compared to these findings.

Realisation of privacy was also related to the experience of satisfaction. Patients' satisfaction has been reported to have a direct and significant correlation with respecting privacy (Nayeri & Aghajani 2010). In this study, satisfaction with care included getting the appointment quickly, trusting health care professionals and interpreters, and knowledge and understanding of the treatment. Long waiting times for health care services have earlier been reported to be one challenge in Somali patients' health care (Fang et al. 2015), and Somali patients have been reported to have higher rates of emergency primary care contacts than native residents (Sandvik et al. 2012). However, the long wait has never before been related to the realisation of privacy. Studies conducted in Muslim countries indicate that the level of privacy in emergency department is considered weak or average (Nayeri & Aghajani 2010). However, the participants did not explain the

relation between the long wait and privacy, i.e. whether the long wait might lead to the high rate of emergency care use, which affects the realisation of privacy

Nurse-patient relationship

Respect and protection of privacy is considered to be important in the relationship between the health care professional and patient. The results of this study indicated that Somali refugees felt that their privacy was respected when the health care professional had knowledge and understanding of Somali culture and when Somali patients had knowledge and understanding of the treatment. Nurse-patient relationship with Somali patients has been reported to require mutual understanding of the culture and health care (eg. Degni et al. 2012). Both Somali refugees and asylum seekers reported to trust the health care professionals in Finnish health care, which is good for the nurse-patient relationship. There are studies, done in different countries, indicating lack of trust, since asylum seekers might fear for their information to be directed to immigration authorities (Asgary & Segar 2011, Jonzon et al. 2015).

When using interpreter, the relationship changes into more complex (eg. Rosenberg et al. 2007). This study revealed cultural challenges related to the use of interpreter in health care. According to this study, the highest rate of violation of privacy was reported for informational privacy. Informational privacy referred to information, which was not shared with others, or was only shared with a limited number of people. In Somali culture, some issues are kept private because of the respect of religion and culture, and to maintain the dignity of the individual, family or community. These issues are usually related to sexuality or mental health problems, both of which are important to share with health care professionals, and might be important also to highlight in the asylum procedure. According to Somali culture, these issues can be discussed with health care professionals; however, interpreters are not considered to be part of the health care team, and their presence might silence the patient.

The confidentiality of the interpreter was questioned by Somali asylum seekers, Somali refugees and by nurses. They all mentioned that the presence of the interpreter might silence the patient. Similar findings have been reported earlier with several different immigrant groups (Upvall et al. 2009, Fatahi et al. 2010, Fang et al. 2015, Krupic et al. 2016). One of the challenges is the cultural background of the interpreter. According to this study, interpreters from Somali culture are used to interpret for Somali patients. Besides adding one extra person, this includes a cultural element in the traditional nurse-patient relationship. While

health care professionals represent the Finnish culture, where the cultural norms and rules of Somali culture are not emphasised, the interpreter represents the Somali culture and the norms, that the patient needs to respect. Many participants, both Somalis and nurses, mentioned the small size of the Somali community in Finland, and the concern related to the fact that interpreters might possess a lot of information, including private information, on the members of this community. The lack of trust and fear of violation of privacy might increase the patient's desire to have family members or friends to act as interpreters, which is also considered to be the main safety net in Somali culture. However, the use of non-professional interpreters is not recommended (eg. Ramirez et al. 2011).

Trust is essential for building a trusting relationship between health care professional, patient and interpreter. However, Somali participants indicated that they do not usually have the same interpreter in their health care encounters, so they have to share their information with several interpreters. Lack of continuity has been reported to be problematic in other studies as well (Fatahi et al. 2008, Hadziabdic et al. 2009, Barnes et al. 2011). It seems that nurses and Somali patients perceived the role of the interpreter in the nursing relationship differently. Similar results have been reported for other health care professionals, such as general practitioners (Fatahi et al. 2008), as well as patients (Fatahi et al. 2010) and interpreters (Butow et al. 2012). While nurses of this study, considered the interpreter to be someone they work with or use in order to get their job done, Somali participants mainly considered the interpreter to be one extra person they have to share health issues with. On the other hand, the nurses had experienced situations where the interpreter and patients were acting as friends, which was not mentioned by any of the Somali participants. Whether this friendship was real and trusting or only behaviour within the cultural norm, it is obvious that the use of interpreters has an effect on the nurse-patient relationship for both health care professionals and patients.

Practical issues in using interpreters

The use of interpreters was not only related to the patient and health care professional, but also to the organisation. The use of interpreters is expensive and costs seem to play a big role, and health care organisations have guidelines on the use of interpreters with patients with different types of immigration status. However, according to the results, nurses made the decision on using interpreters mainly based on the rights of the patient and the need for interpreters. Nurses wished for better availability of interpreters and better access to interpreter services. In earlier studies, costs have been decreased and availability has been

improved by using tele-interpreters or other methods of non-face-to-face interpreters (Ramirez et al. 2008). Nurses had learned to use interpreters through their work. A need for formal education on the topic was mentioned. Earlier studies have reported that education on working with interpreters and the use of interpreter services helps the health care professionals to understand better the elements in use with interpreters (Hsieh 2010, Baurer et al. 2014).

In Finland, the education of interpreters varies from University education to informal education provided by the interpreter services. This means that the language skills may be based only on experience. There is a lack of interpreters specially trained to medical interpretation. These specially trained interpreters, called medical interpreters exist in some countries. The variety of education, and lack of special competence in medical terminology, raises the question of the accuracy of the interpretation. These results indicated that, both nurses and Somalis consider the language skills of the interpreter to be very important and challenging to evaluate and it was sometimes questioned. The language skills have also been considered important in earlier studies since mistakes in interpretation can have clinical consequences (Flores et al. 2012).

6.1.2 Use of interpreters in health research with asylum seekers

When it comes to the use of interpreters in health research, the literature review revealed that there is a lack of publications focusing only on methodological issues in research with asylum seekers. Asylum seekers are often combined with other immigrant groups or with other vulnerable populations (e.g. Fang et al. 2015, Enticott et al. 2017); as a result, attention on asylum seekers' special life situation is lacking. In this literature study the aim was to describe the methodological factors related to health research with asylum seekers.

The factors related to the planning of the research were acknowledgement of asylum seekers' immigration status, choosing the research methods, recruiting asylum seekers and choosing the interpreter. Asylum seekers differ from other immigrant groups, such as refugees, because of their post-settlement experiences. In literature, the pre-settlement experiences are acknowledged, especially when combining asylums seekers with refugees. Only few articles focused on the impact of post-settlement experiences (Ruppenthal et al. 2005, Ogilvie et al. 2008).

When recruiting asylums seekers, a direct approach in recruiting is suggested (Ogilvie et al. 2008); however, this usually requires co-operation with

interpreters, reception centres and/or community leaders (Ruppenthal et al. 2005). It also requires good knowledge of different immigration services, such as interpreter services, on the part of the researcher. Including community leaders or other community members in the recruitment is also a way of showing respect to the culture and its norms. When it comes to informed consent and decision-making, there is a clear difference between individual cultures, such as Western cultures, and collective cultures. In some cultures, the Western way of individual decision-making can even be harmful for the participant (Birks et al. 2007, Halkoaho et al. 2016). The cultural aspects of decision-making have been acknowledged (WMA 2013); however, more detailed guidelines are still lacking.

The interpreter has an important role in health research with asylum seekers. The interpreter has impacts on the whole research process (Ogilvie et al. 2008). Multiple competences are expected from the interpreter. The language competence affects the validity of the research while the cultural background might affect the level of activity of the participants. It is suggested that the interpreter should also have competence in the research field (Kapborg & Berterö 2002). These requirements pose challenges for finding suitable and competent interpreters. The educational level of interpreters varies from no education to university degree. In Finland, interpreters from asylum seeker cultures (e.g. Somali culture, Afghanistan culture) are usually themselves immigrants with no formal education in interpreting.

The factors related to the conduct of the research included communication through the interpreter, creating a respectful and trustful environment and recognition of cultural aspects. It is important to recognise practical factors in communication, such as using non-complicated language, as well as interpreting methods. They have an impact on the trustworthiness of the research (e.g. Squires 2008), and on the relationship between the participants and the researcher (e.g. Plumridge et al. 2012). Different interpreting methods have been reported to have different impacts on research. An active method is suggested to promote a trusting relationship between the participants and researcher (Plumridge et al. 2012) while a passive method is suggested to increase the trustworthiness of the research (Squires 2008). When conducting research with asylum seekers, creating a trusting and safe environment is needed (Ogilvie et al. 2008, Im et al. 2014), which requires flexibility and careful consideration of the interpreting method on the part of the researcher.

6.2 Trustworthiness of the study

First, the trustworthiness of this study is assessed in terms of credibility, transferability, dependability and confirmability (Lincoln & Guba 1985, Miles et al. 2014). Second, special attention is given to the use of interpreter which may affect the results of the study (Halcomb et al. 2007, Squires 2009). The trustworthiness of the use of interpreter is assessed by the criteria by Squires (2009).

The credibility criterion involves establishing that the results of descriptive research are believable from the perspective of the research participant (Lincoln & Guba 1985). Credibility can be assessed by the decision about the focus of the study, selection of context and participants, and approach to gathering data (Graneheim & Lundman 2004). In data collections (I, II, III) the credibility of the study was tested using pilot interviews or questionnaire. In data collection with interviews, pilot interviews were done to check the conduct, timing and the themes and questions. No changes were made based on the pilot. In the focus group interviews the pilot showed that the term “privacy” varies in Somali language dialects. In the beginning of every interview, the interpreter and participants discussed the term in order to find a common word for the interview. Either the Somali word “xad” meaning “limit” or the English word “privacy” was used. The questionnaire was piloted with three Somali culture representatives. No changes were made based on the pilot, but these three were not included into the data, since the participants of the pilot did not meet the criteria of participation in the study. In the interviews, preliminary findings were discussed with the participants within the last interviews, and all results concerning Somalis, the analysis and the final findings were discussed with Somali culture representatives. All data analyses are presented in the text and tables in order to ensure the credibility of the analysis (Graneheim & Lundman 2004).

Transferability refers to the extent to which the findings can be transferred to other contexts (Lincoln & Guba 1985). Transferability can be improved by giving a distinct and clear description of culture and context, selection and characteristics of participants, data collection and the process of analysis (Graneheim & Lundman 2004). In this study, the characteristics of the participants are clearly described (I, II, III). In order to increase transferability, the participating reception centres (I), health care centres (III) and other institutes (II) were chosen based on their large number of suitable participants for this study.

Dependability refers to the researcher's decisions during the analysis process and to the degree to which data change over time and whether other researchers would be able to repeat the study (Lincoln & Guba 1985, Graneheim & Lundman 2004), and whether the process of the study is consistent (Miles et al. 2014). In this study, the process of the study is reported clearly and systematically so that another researcher would be able to follow it, and the results are reported using appropriate quotations (Graneheim & Lundman 2004). However, the personal and unique experiences cannot be repeated. During the data analysis, the researcher went back to the original data, including the audiotapes, in order to confirm that all the statements and comments were properly observed and interpreted. One of the major limitations of this study is that data of sub-study 3 (III) dates back ten years, which can affect the trustworthiness of the results. During the last ten years, the number of immigrants and the major nationalities of immigrants have changed, which could affect the nurses' experiences in health care with immigrant patients. However, the participating nurses had several years of experience in working with immigrants and interpreters, and since there are no changes in interpreters' basic education or nurses' education on working with interpreters, the results can be accurate today.

Dependability can also be improved by conducting an audit trial. An audit trial can also be used to increase *confirmability*, which refers to the objectivity of the data (Lincoln & Guba 1985). During the whole process of the study, there has been an ongoing, active and open dialogue with the participants of the study and the Somali community. The analysis and the results were discussed with members of the Somali community, including some participants of the study, in order to confirm the accuracy of the results and to refer truthfully to the original data.

The trustworthiness of the use of interpreter is assessed by the following criteria: conceptual equivalence, interpreter credentials, interpreter's role and methods (Squires 2009).

Conceptual equivalence states that 1. The rationale is provided for why the analysis occurred in a different language than the participants' language, 2. A translation lexicon is developed to ensure conceptual equivalence, and 3. The translation has to be validated by a qualified bilingual individual who is not directly involved with the data collection or the initial translation. (Squires 2009.)

In this study, the rationale for using different languages than the participants' language was the researcher's lack of Somali language competence and the Somali participants' lack of Finnish language competence (I, II). A translation

lexicon related to the term “privacy” was formed for the focus group interviews (I), since several words are used in the Somali language for the concept “privacy”. In order to increase the conceptual equivalence, a discussion about privacy and the right term was conducted at the beginning of every focus group interview. Each group decided which term for “privacy” would be used during the interview (I). In the second sub-study (II), the concept of “privacy” was explained by the definition created in sub-study 1 (I) including the content and importance of privacy. In order to validate the translation, the data were partially re-interpreted by another Somali interpreter who was not involved with the data collection. Even though careful attention was given to the interpretations and translations throughout the study process, there is a risk of lingual misunderstanding of the concept of privacy, which could affect the trustworthiness of the results.

Interpreter credentials states that 1. The interpreter’s qualifications are briefly described, 2. The researcher’s level of language is described, and 3. The researcher’s or interpreter’s identity in contrast to that of the participants is described. (Squires 2009.) The interpreters used in this study (I, II) had a high level of language and cultural knowledge in Somali and Finnish. All interpreters also had nursing education and wide working experience in nursing and interpreting. Two of the interpreters also had experience in health care research. The position of the interpreters and researcher was openly described during the data collections and in the report of the study.

Interpreter’s role and method states that 1. The role of the interpreter is described, 2. The use of the interpreter during the research process is described, 3. The conductor and language of the analysis is identified. (Squires 2009.) In this study, the role of the interpreters was discussed with the interpreters before the data collections (I, II). An active interpretation method was chosen in order to establish a trusting relationship between the participants and the researcher and to improve the flow of conversation (Plumridge et al. 2012). This method has been criticised for decreasing the trustworthiness of the study since the interpreter can only summarise the conversation to the researcher, and because the interview is guided also by the interpreter, not exclusively by the researcher (Pitchforth & van Teijlingen 2005). In order to avoid the summarisation of the conversation, the interpretations were audiotaped (I), and in situations where the interpretation did not match the original conversation, the interpretation was re-checked. The interpreters were women, as was the researcher, which may have a negative affect on the male participants’ willingness to talk about sensitive issues. However, none the participants (I, II), male or female, had any problems with the

interpreters' gender when it was discussed before the data collections. Despite the careful planning and agreement of the participants to have a female interpreter, the level of disclosure can be questioned (Halcomb et al. 2007). The analysis was done by the researcher in the Finnish language and discussed with a Somali person in order to increase the cultural trustworthiness.

6.3 Implications

The aim of this study was twofold. First, the aim of the empirical phase was to describe the content, importance, and realisation of privacy for Somali patients, and factors related to the use of interpreters in health care. According to the literature review, there is a lack of studies in this field. Based on the results, privacy in Somali culture is related to the collectivistic nature of Somali culture. Religion, culture and community guide individuals' perceptions of privacy. Even though this study was done in the field of nursing ethics and the results are based on clinical nursing, the results can be generalised to a wider field in health care. Second, the aim of the methodological phase was to identify factors related to the use of interpreters in health research with asylum seekers. Previous articles related to the use of interpreters in health research did not acknowledge asylum seekers' post-settlement experiences, and they combined asylum seekers with other immigrant groups, such as refugees. According to the study results, the following implications for nurse education, nursing practice and further research are presented:

Implications for nurse education

This study revealed a need for understanding different cultural values, including privacy, in health care. In the future, the number of asylum seekers and refugees in health care will increase, creating a need for multicultural understanding of nursing ethics. The foundation of nursing ethics is in professional education, which is why education on health care ethics should also include a non-Western ethical perspective.

The use of interpreters is important when health care professionals and patients do not have a common language. Working with interpreters in health care has been described as challenging and it requires diverse competence. In this study, nurses had learned to use interpreters in practical work and they considered it to be challenging. According to previous studies, education on how to work with interpreters improves understanding on the effects of the interpreter on the nurse-patient relationship and improves skills in working effectively with interpreters.

Therefore, there is a need to ensure that health care professionals receive education in the perspective of multicultural ethics and the use of interpreters.

Implications for nursing practice

This study revealed a need for health care professionals to understand and acknowledge different cultural values. Understanding the cultural and collective element of privacy in health care might help health care professionals to understand the differences in what is private for the patient and for the health care professional. A mutual understanding is required for necessary interventions that may violate patients' privacy.

Previous studies have recognised the importance of privacy and gender concordance for Somali women. This study revealed the importance of gender concordance and privacy for Somali men as well, and the fact that also men had experienced violation of privacy in health care. In health care, recognition of gender concordance for both men and women could improve the realisation of privacy.

In this study, several factors related to the use of interpreters were identified, and the use of interpreters was considered a major element in the nurse-patient relationship. The continuity of using the same interpreters with the same patients promotes a trusting and private relationship between the nurse, patient and interpreter. This demands better collaboration between health care services and interpreter services. The possibility of educating interpreters specialising in the terminology of health care should be considered.

According to the results, cultural norms might silence the patient when the interpreter is present. The availability of interpreters was also considered challenging. In previous literature, positive results improving patients' privacy have been reported when using non-face-to-face methods. The use of tele-interpretations or other methods might improve the realisation of privacy and the availability of interpreters.

Implications for further research

For health care ethics and its research, this study revealed a new understanding of the concept of privacy. In this study, privacy was studied in the Somali culture. In Western countries, privacy is often seen as an individual phenomenon. First, the results of this study revealed that the collectivism of the Somali culture guides the contents and importance of privacy. The social, cultural and collective

elements of privacy and their effect for individuals should be described more thoroughly in other non-Western or collective cultures. In addition, longitudinal research is needed to understand the effect of post-settlement experiences and acculturation in these elements of privacy. Second, since the earlier studies mentioning privacy of Somali patients, are usually done using privacy's related concepts (such as secrecy, confidentiality), and the term "privacy" varies in Somali dialects, there is a need for deeper understanding on the conceptual differences of the privacy and its related concepts in Somali culture and health care.

For health care ethics, this study described the factors related to the realisation of privacy from the perspective of Somali refugees. The realisation of privacy for Somali patients should be studied further and the results of this study can be used to create an instrument measuring privacy in Somali culture. With such an instrument the realisation of privacy could be studied using more structured methods. Special attention should be given to the differences of privacy for Somali asylum seekers, refugees and other immigrants.

This study revealed that the use of interpreters has an impact on the relationship between the patient and health care professional. Interpreters are usually seen as tools for language; however, their impact on the nursing relationship is crucial. A better understanding of this impact is needed through further study, describing the relationship by comparing the perspectives of health care professionals, patients and interpreters.

The methodological part revealed, that there is a lack of methodological articles related to health research with asylum seekers, and previous articles related to the use of interpreters in health research do not acknowledge asylum seekers' post-settlement experiences and combine asylum seekers with other immigrant groups, such as refugees. Asylum seekers are considered to be a vulnerable group, needing a special attention in health research, during the whole research process. Further research is needed also on different research methods and the use of interpreters and their ethical aspects in health research with asylum seekers.

7 CONCLUSIONS

The aim of this study was twofold. First, the aim of the empirical phase was to describe the content, importance and realisation of privacy for Somali patients, and the use of interpreters in health care. According to the results, privacy in Somali culture is related to the collectivistic nature of the Somali culture. The content of privacy, visual, physical and informational, can be shared with no one, family members, persons of the same gender or health care professionals and interpreters in health care. In health care, health care professionals are trusted and according to Somali culture, private issues related to health can be shared with health care professionals.

Interpreters are not considered to be part of the health care team, and their presence is considered to be a problem when it comes to realisation of privacy. Both men and women had experienced violation of privacy and considered respect of privacy to be important in health care. Privacy is seen as important because it is a way of respecting religion, culture and community, and it protects the dignity of the individual, family and community. Individuals' freedom to share private issues is guided by religion and culture.

Several factors related to the use of interpreters in health care and health research were identified. The use of interpreters has an impact in both health care and health research. Even though interpreters decrease language barriers, their presence creates challenges in the relationship between the health care professional/researcher and the patient/participant.

In summary, this study described new knowledge for nursing ethics research on the concept of privacy in Somali culture, and for practical nursing ethics on the realisation of privacy with Somali patients. This study also described the factors related to the use of interpreters, which can be implemented in both health care practice and health research.

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APPENDICES

Appendix 1. Asylum seekers and refugees in Finland 1990-2017 (Finnish Immigration Service 2018)

| Year | Asylum seekers in Finland | Somali asylum seekers in Finland | Somali quota refugees | Resident permits for Somalis |
|------|---------------------------|----------------------------------|-----------------------|------------------------------|
| 1990 | 2,743 | 1,441 | | |
| 1991 | 2,137 | 320 | | |
| 1992 | 3,634 | 171 | | |
| 1993 | 2,023 | 155 | | |
| 1994 | 839 | 177 | | |
| 1995 | 854 | 133 | | |
| 1996 | 711 | 140 | | |
| 1997 | 973 | 184 | | |
| 1998 | 1,272 | 135 | | |
| 1999 | 3,106 | 73 | | |
| 2000 | 3,170 | 28 | | |
| 2001 | 1,651 | 54 | | |
| 2002 | 3,443 | 91 | | |
| 2003 | 3,221 | 91 | 15 | |
| 2004 | 3,861 | 253 | 11 | |
| 2005 | 3,574 | 321 | 0 | |
| 2006 | 2,324 | 92 | 38 | 257 |
| 2007 | 1,505 | 82 | 0 | 523 |
| 2008 | 4,035 | 1,181 | 1 | 563 |
| 2009 | 5,988 | 1,180 | 1 | 534 |
| 2010 | 4,018 | 571 | 0 | 522 |
| 2011 | 3,088 | 356 | 1 | 595 |
| 2012 | 3,129 | 203 | 23 | 473 |
| 2013 | 3,238 | 217 | 11 | 760 |
| 2014 | 3,651 | 411 | 0 | 666 |
| 2015 | 32,476 | 1,981 | 1 | 411 |
| 2016 | 5,651 | 432 | 0 | 401 |
| 2017 | 5,059 | 130 | Data not available | Data not available |

Appendix 2. Questionnaire in Finnish

Questionnaire in Finnish

Arvoisa vastaanottaja,

Teen väitöskirjatutkimusta somalialaisten pakolaisten ja turvapaikanhakijoiden yksityisyydestä terveydenhuollossa. Tarkoituksena on selvittää, miten yksityisyyttänne kunnioitetaan hoitajan tapaamisella, kun paikalla on tulkki.

Pyydän ystävällisesti Teitä osallistumaan tutkimukseen täyttämällä liitteenä olevan kyselyn. Kyselyssä ei kysytä nimeänne, eikä mitään muita tietoja, joista teidät voisi myöhemmin tunnistaa. Kaikkia kysytyjä tietoja käsitellään luottamuksellisesti vain tämän tutkimuksen tarkoitukseen, niitä ei luovuteta viranomaisille, eikä terveydenhuollon henkilöstölle.

Tutkimukseen osallistuminen on Teille täysin vapaaehtoista, eikä tutkimukseen osallistuminen tai osallistumatta jättäminen vaikuta terveyspalveluihinne, eikä muihinkaan saamiinne palveluihin. Tutkimuksen tulokset julkaistaan väitöskirjassa ja tieteellisissä artikkeleissa niin, ettei kenenkään osallistujan henkilöllisyys paljastu. Edes tutkija ei tule tietämään osallistujien nimiä.

Jos haluatte osallistua, täyttäkää siis tässä mukana oleva kaavake somaliaksi ja antakaa se suljetussa kirjekuoressa, joka on tässä mukana, hoitajalle/vastaanottoon. Suljetut kirjekuoret toimitetaan tutkijalle, eikä hoitopaikkanne henkilökunta näe missään vaiheessa vastauksianne.

Jos haluatte kysyä minulta jotain liittyen tähän tutkimukseen, voitte lähettää minulle sähköpostia joko suomeksi tai englanniksi.

Ystävällisin terveisin,

Väitöskirjan ohjaaja

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1. Kuinka kauan olette ollut Suomessa? _____ vuotta _____ kuukautta
2. Oletteko mies _____ vai nainen _____
3. Kuinka vanha olette? _____ vuotta
4. Onko Teillä tulkki käytössänne vastaanotolla? On aina _____ On joskus _____
Ei ole _____
5. Onko Teillä yleensä sama tulkki kun tapaatte hoitajan? Kyllä _____ Ei _____
6. Minkä maalainen tulkki Teillä yleensä on? Somalialainen _____
Suomalainen _____
7. Oletteko ollut tyytyväinen tulkkiin? Kyllä _____ En _____
Miksi? _____
8. Kuinka usein käytte terveydenhoitajan tai sairaanhoitajan vastaanotolla?
Joka viikko _____ Joka kuukausi _____ Harvemmin _____
9. Käyttökö vastaanotolla oman terveyttenne vuoksi, vai jonkun toisen kuten lapsenne vuoksi?
Oman terveyteni _____ Lapseni vuoksi _____ muun perheenjäsenen vuoksi _____
10. Minkälainen oma terveyttenne tällä hetkellä on? Hyvä _____ Huono _____
11. Oletteko joskus joutuneet paljastamaan itseänne toiselle henkilölle tahtomattanne sairaanhoitajan vastaanotolla?
Kyllä _____ Kenelle/keille? _____ Miksi? _____
En _____
12. Onko joku henkilö joskus koskenut teihin tahtomattanne sairaanhoitajan vastaanotolla?
Kyllä _____ Kuka/ketkä? _____ Miksi? _____
En _____
13. Oletteko joskus joutuneet paljastamaan sellaista tietoa, jota ette olisi halunnut kertoa sairaanhoitajan vastaanotolla?
Kyllä _____ Kenelle/keille? _____ Miksi? _____
En _____

Seuraaviin kysymyksiin voitte vastata kertomalla tietystä tapaamisesta tai tilanteesta, jonka olette kokenut joskus suomessa terveydenhuollossa. Kertokaa asia mahdollisimman tarkkaan ja yksityiskohtaisesti.

14. Millainen on mielestänne ollut hyvä tapaaminen hoitajan kanssa kun paikalla on ollut tulkki? Kirjoittakaa millainen on ollut tilanne, jossa Teitä ja Teidän yksityisyyttä on kunnioitettu, eikä / tai Teitä ole hävettänyt tapaamisen aikana tai sen jälkeen.

15. Millainen on mielestänne ollut huono tapaaminen hoitajan kanssa kun paikalla on ollut tulkki? Kirjoittakaa millainen on ollut tilanne, jossa Teitä ja Teidän yksityisyyttä ei ole kunnioitettu, ja / tai Teitä on hävettänyt tapaamisen aikana tai sen jälkeen.

Kiitos osallistumisestanne!

Appendix 3. Questionnaire in Somali

Aqriyaha sharafta leh,

Waxaan sameenayaa buugeygii qalinjabinta kuna saabsan qaxootiga somalida iyo shaqsiyada waqtiga gaargaar caafimaadeed. Ula jeedada waa in aan ogaano sidee loo xushmeeya sharaftiina shaqsiyeed marka turjumaanka uu joogo.

Waxaan si sharafleh idiin weydiisanaa in aad ka qeeb qaadataan baaritaankan aadna buuxisaan su'aalaha warqada la socoto. su'aalaha lagu ma weydiinayo magacaaga iyo wixii lamid ah oo adiga laguugu garankaro. Waxaan u isticmaaleynaa baaritaankaan kaliya, si aamin cid kalena lama siinayo sida dowlada ama shaqaalaha caafimaadka.

Baaritaankan adiga ayaa go'aan u leh, qasab ma'aha. ka qeyb qaadashada ama hadaad iska dhaafto saameeyn kuma yeelaneyso gargaarka caafimaadkaada, iyo wixii la mid ah. Waxaa laguna soo daabici doonaa buugeyga qalinjabinta iyo jornaalada cilmibaarista, ayadoo aanan la garaneyn oo aanan magaca la sheegeyn. Baaraha xataa magaca ma yagaano.

Hadaad rabto in aan ka qeeb qaadato buuxi waraaqada kadibna baqshada ku xer, oo la socoto,

Kalkaaliye/Xafiisk qaabilaadka. Baqshadaha oo xiran ayaa loo diraa baaraha, mana arkaayaan jabaabtiina shaqaalaha gargaarka caafimaanka .

Haddii aad doonaysid inaad I waydiiso arrintan wax ku saabsan fadlan ii soo dir Email, waxaad iigu soo qori kartaa su'aalahaaga Af ingiriis ama Af Finnish.

Waad mahadsan tihiin,

Wareysi qaade / Cilmi baaris buug:

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1. Ilaa intee ayaad Finland daganeed ? _____ Sanadood _____ bilal
2. Nin _____ ama Naag _____
3. Meeqo jir ayaad tahay ? _____ sanadood
4. Tarjume mar walba ma kula socdaa ? Haa mar walba _____ Mar mar _____
Maya _____
5. Marwalba ma isku turjumaan ayaa kula socdaa? Haa _____ Maya _____
6. Tarjumahaada wadankee ayuu u dhashay ? Somali _____ Finnish _____
7. Maku qanacsan tahay tarjumahaada? Haa _____ Maya _____
Sabab? _____
8. Booqashada ama goormee ayaad u imaadaa neersida?
Sitimaan walba _____ Bil walba _____ Marmar _____
9. Markaad imaano halkaan ma daryeelkaaga , ama qof kale sida cunugaada ?
Daryeelkeyga _____ Cunugeyga _____ Qof kale reerka kamid ah _____
10. Hadda caafimaadkaada ka waran? Wuu fiican yahay _____
Wuu xun yahay _____
11. Waligaa cowradaada ma baneysay adigoo rabin kalkaalisada oo lalajoogo?
Haa _____ Kuma/kuwe? _____ Sabab? _____
Maya _____
12. Weligaa qof maku taabtay adigoo rabin kalkaalisada oo lajoogtit?
Haa _____ Kuma/kuwe? _____ Sabab? _____
Maya _____
13. Waligaa ma sheegtay arin aadan rabin in aad sheegto, markad la joogtay kalkaaliyada?
Haa _____ Kuma/kuwee? _____ Sabab? _____
Maya _____

Su'aalaha waxaan ugu jabaabi kartaa in aan inoo sheegto is arag ama arin horay u soo dhacday, kana dhacday gargaarka caafimaanada finland. u sheeg adigoo si fiican inoogu faahfaahinaayo.

14. Goormee ayaad la heshay kulan fiican kalkaaliyada uuna tarjumaha joogay? Inoo qor xaalada sidey ahaeyd, ma dareentay in adiga iyo shaqsidaya sharaftaaada la'idiin xushmeeyey/ ama lagu ceebeeyay waqtiga aad kalkaaliyada la joogtay.

15. Sidee ayey kula aheyd hadii y jiro kulan aad u xumaa oo aad kalkaliyada la qaadatay uuna tarjume joogay? Inoo qor xaalada sidey aheed, dareentay in adiga iyo shaqsidaya sharaftaaada la hushmeeneyn / ama lagu ceebeeyay waqtiga aad kalkaaliyada la joogtay / gabadha caa Finaada nersinada.

Waad ku mahadsantahay ka soo qeyb galkaaga!

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