



## **The Role of Cultural Factors on Breast Cancer Screening Participation.**

Community-based pilot study assessing the influence of cultural factors on health behaviours regarding breast cancer screening among non-Dutch mother tongue women in the Netherlands.

Master Thesis Intercultural Communication

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In collaboration with Mammarosa Foundation (*Stichting Mammarosa*)

## Preface

Before you lies my Master thesis, titled “The Role of Cultural Factors on Breast Cancer Screening Participation.” This pilot study was in collaboration with the Mammarosa Foundation (*Stichting Mammarosa*), with whom I first met on November 22nd, 2019. During our early meetings we established the main goal and approach of this study. However, due to the COVID-19 pandemic, it became essential to change our original plan and adapt it to the unforeseen circumstances. Fortunately, the Mammarosa Foundation was empathic to the situation and open to a new direction. Ultimately, the results of our collaboration provide an excellent start for future research and new recommendations to increase breast cancer screening participation among the target group.

I would like to thank the Mammarosa Foundation for their openness and thoughtfulness throughout our collaboration. There is no doubt that we will stay in touch with each other to promote future research in this field. My gratitude also goes to my thesis’s supervisor, Dr Tessa van Charldorp, who was always able to provide me with intensive guidance and support.

Jesse David Marinus

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## Abstract

Breast cancer screening programs in the Netherlands offer high-risk women between the ages of 50 and 75 a free mammography every two years, with the purpose of increasing early detection and lowering the mortality rate. However, not all high-risk women have equal access to breast cancer screenings due to different cultural factors that prevent them from performing the recommended health behaviour. The present community-based pilot study analyses the possible impact of health literacy, cultural perception, and past experiences of non-Dutch mother tongue speaking women on the accessibility of breast cancer screening.

To answer the research question, data was collected using a self-administered digital questionnaire through snowball sampling ( $n = 38$ ) in collaboration with Mammарosa Foundation. The results show that the chosen tool and distribution method are not suitable for the high-risk group ( $n = 2$ ), however, a first insight into the influence of different cultural variables on participation in breast cancer screenings is given. Nonetheless, the results do provide evidence that negative perception of Dutch healthcare creates barriers for the non-high-risk group ( $n = 36$ ), which are also influenced by education level, health literacy, and language proficiency.

These findings highlight the need for early-on intervention for non-high-risk individuals, with emphasis on improving their perception of Dutch healthcare and increasing open communication about breast cancer, which is especially crucial as they will be the future high-risk group. In addition, the recommendation is to create role models, accessible information on breast cancer, as well as patient-focused and intercultural communication techniques for healthcare professionals, all of which should be adjusted to the women's language proficiencies, health literacies, and educational level. Finally, to improve the general adoption of new health behaviour, the focus should be on improving the target population's Dutch language proficiency and health literacy skills.

## Table of Contents

Preface.....	2
Abstract.....	3
Introduction.....	5
Theoretical Framework.....	7
Culture and New Public Health.....	7
Culture and Health Belief Model.....	8
Social Environment and Health.....	9
Cultural Factors and Breast Cancer Screening.....	10
Research Question.....	14
Methods.....	15
Community-Based Research.....	15
Participants.....	16
Instruments.....	17
Distribution.....	19
Analyses Closed-Ended Answers.....	20
Analyses Open-Ended Answers.....	20
Results.....	22
Descriptive Statistics.....	22
Inferential Statistics.....	27
Content Analysis.....	33
Discussion.....	36
Discussion High-Risk Group.....	36
Discussion Social Environment.....	38
Limitations.....	41
Recommendations.....	42
Reflection with the Community.....	43
Conclusion.....	44
Bibliography.....	45

## Introduction

One in every seven women in the Netherlands will get diagnosed with breast cancer somewhere during their lifetime. Especially women between the ages of 50 and 75 are at a higher risk due to their increased susceptibility to the disease and consequential mortality (RIVM, 2019). As the chances of recovering are considerably better when it is diagnosed in its early stages, the Dutch government created a nationwide campaign to promote breast cancer screening among women who belong to the high-risk group. The breast cancer screening commonly consists of a *mammography*, which is an X-ray of the breast tissue to observe any abnormalities ("bevolkingsonderzoek borstkanker", n.d). However, not all high-risk women have equal access to breast cancer screenings, which could be the direct result of different cultural factors that prevent them from performing the promoted health behaviour. It is thus crucial to understand which are the factors that could prevent them from participating in breast cancer screenings.

This pilot study aims at providing first insights on the cultural factors that might create barriers to the accessibility of breast cancer screenings for non-Dutch mother tongue speaking women<sup>1</sup>. To achieve this, the research was built in collaboration with the target group through a community-based approach. This meant that they were involved in setting and defining the goals as well as choosing the most fitting methods to achieve them. Furthermore, due to the pilot nature of this study the feasibility and suitability of the chosen tools, methods, and approaches for future research was also tested.

The community is being represented by the Mammarosa Foundation (*Stichting Mammarosa*), which is a small-scale volunteer organisation that offers information, support, and guidance to non-Dutch mother tongue speaking and lower literacy women who have been diagnosed with breast cancer. One of the goals of this study was to help the Mammarosa Foundation understand how cultural factors such as health literacy, social environment, as well as the experience and cultural perception on healthcare, can influence the target group's breast cancer screening participation. On the other hand, the findings of this community-based research (CBR) also contributes to the scientific understanding of non-Dutch mother

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<sup>1</sup> In this study the target population is called *non-Dutch mother tongue speakers* instead of the more commonly used term: *non-Dutch native speakers*. This was decided together with the Mammarosa Foundation as many of these women do have native Dutch language proficiency, but it is not their only L1.

tongue speaking women's health behaviours in breast cancer screenings. For this purpose, a quantitative method consisting of a self-administered digital questionnaire (n = 38) was selected for the collection of the data. It is important to highlight that this study does not take an essentialist approach to culture, which means that it did not analyse its results based on cultural heritage groups.

This study consists of six sections. The first one explores the relevant literature on new public health, the health belief model, social environment, and summarises previous empirical studies on cultural factors and breast cancer screenings. This will create the basis to present the research question. After this a thoroughly explanation of the methods is given, which include the CBR approach and the operationalization of the questionnaire. The derive findings from quantitative analysis are presented in the result section. Building on all the previous segments, the discussion part will analyse the data, including a conceptual diagram, and attempts to answer the research questions as well as illustrate its limitations. Additionally, the advices provided to the Mammarosa Foundation will also be presented in this section as well as the organisation's reflection on them. The study is wrapped up with a conclusion segment which highlight the presented essentials notions.

## Theoretical Framework

The foundation for the theoretical considerations of this thesis are based on both the new public health and the health belief model. These two angles are used to argue for the need to observe and analyse cultural factors in public health research. This includes the role of social environments as a factor in health behaviours. After the theoretical foundation has been built, the findings of previous empirical studies outline which cultural factors influences breast cancer screening participation.

### Culture and New Public Health

The discipline of *public health* was described by Winslow in 1952 as the science and art of ensuring that every individual in the community has a standard of living suitable to the maintenance of *good health*<sup>2</sup>. At that time, public health predominantly focussed on the behavioural, biostatistical, and epidemiological aspects of health. However, the discipline has moved to a new era, called *new public health*, which focusses on the cultural, sociological, and anthropological understandings of inequalities in health, health experience, accessibility, and perception of healthcare. The new approach places importance upon the studying of how health knowledge functions in different socio-cultural contexts (Tulchinsky & Varavikova, 2010).

This new approach towards public health perceives the role of culture on health in two complementary ways: from a sociological and from a cultural anthropological perspective. The former defines culture as the "patterned ways of thought and behaviour that characterise a social group, which are learned through socialisation processes and persist through time" (Coreil, Bryant, & Henderson, 2001, p. 29). On the other hand, according to the cultural anthropology perspective, culture is defined as the "unique shared values, beliefs and practices that are directly associated with health-related behaviour, indirectly associated with a behaviour, or influence acceptance and adoption of the health education message" (Pasick and D'Onofrio, 1996, p.144). However, both understandings can fall in the realm of *soft essentialism*. They are *essentialist* because in both cases certain cultural factors are inherently attached to a specific cultural or ethnic group, while they have a *soft* quality that allows for a *third space*; a realm where socio-cultural constructs of one's identity are transcended and intercultural and person-oriented approaches are possible (see Holliday, 2006).

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<sup>2</sup> *Good health* in this thesis does not mean the medical definition of health: being without disease. Instead it is the person's own subjective assessment of what they consider to be good health (see Waller, 2015)

The soft essentialist notion of culture has been criticised by several scholars who denounced its neoliberal commodification and quantification of culture, claiming that it creates barriers to achieve an in-depth understanding of interculturality. According to them, soft essentialism sustains neo-racist suggestions of culture where an *Us* and a *Them* are created, instead of questioning the ideological construct of essentialist culture (Holliday & MacDonald, 2019). However, the present study argues that a complete elimination of an essentialist approach to culture will create blind spots, as such analysis can provide insight into how societal processes systematically treat specific groups with a shared culture differently. Thus, culture should be studied based on individuals having shared aspects rather than as a general ideological construct of one entire group. Giving this consideration, it is vital to not use cultural groups (or related concepts) as the primary variable when researching barriers in health. Instead, the focus should be on cultural factors that influence a phenomenon, which in this study's context is the ineffective and inaccessible of breast cancer screening programs (see Rajaram & Rashidi, 1998)

In this study, the criticism on soft essentialism was incorporated by approaching the culture of the participants through the theory of *migration adaptation* (Berry, 1992), which is also referred to as the psychological adaptation of migrants (see Kuo, 2014). According to this theory, migrated individuals do not exclusively adhere to either the dominant cultural in their country of residence or that from their country of origin. Instead due to the interaction of the two cultures a new cultural identity is created (Kuo, 2014). Nevertheless, this new identity is not the same for all individuals with a shared cultural heritage as they adjust, react, or withdraw differently when the two cultures interact. Therefore, it is not possible to expect cultural factors regarding health to be the same among individuals with similar migration backgrounds.

### **Culture and Health Belief Model**

One of the most used approaches to analyse and understand individuals' tendency to perform health behaviours is the *Health Belief Model* (HBM). It is built upon four notions that help understand an individual's health-related behaviours, such as participating in breast cancer screening. These are their perceived *severity* and *susceptibility* of a disease, as well as their perception on achieved *benefits* and *barriers* to act (Cummings, Jette & Rosenstock, 1987; Rosenstock, 1974). In 1988, *self-efficacy*, which refers to the perception of one own's competences to adopt a health behaviour, was added to the HBM (Rosenstock, Strecher & Becker, 1988). Several studies on breast cancer screening and self-examination found that low



self-efficacy led to lower positive health behaviours (Noroozi, Jamond & Tahmasebi, 2011; Jirojwon & Maclellan, 2003; Taymorri & Habibi; 2014; Xie et al., 2019).

In the HBM, cultural factors can, directly and indirectly, impact the health behaviours of individuals, as they can influence their definition of good health, sickness, how they explain pain, and their selection of medical assistance (Lim et al., 2009). In addition, factors such as language proficiency and religious beliefs directly affect the individuals' tendencies to perform the recommended health behaviour (Cummings, Jette & Rosenstock, 1987). For example, a specific cultural perspective towards breast cancer screening can be that it is as a test for individuals who are experiencing symptoms, rather than a preventive tool (Kandula, Wen, Jacobs & Lauderdale, 2006). Also, for many women talking about breast cancer can be a taboo, as it may be considered a punishment based on religious beliefs (Parhizkar, Nazari & Hassan, 2012; Kağıtçıbaşı, 1998). However, even though current studies show relations between cultural factors and health behaviours, there is still limited research on the effects that they have on health beliefs (Lim et al., 2009). In particular about the correlation or causation between cultural factors and health behaviours. Hence, extra attention must be given to the nature of these relationships.

### **Social Environment and Health**

The social environment of individuals, that is their family and friends, is an essential part of their culture. It can have a significant influence on their tendency and performance of health behaviours, mainly because of two contrary phenomena: social constraints and social support. *Social constraints* are factors from the social environment that hinder the individual in achieving or executing certain health behaviours (see Andrykowski & Pavlik, 2011; Schmidt & Andrykowski, 2004). These can be both formal, for example public policy, and informal, which include cultural practices such as taboos and lack of open communication. On the other hand, *social support* refers to the factors that facilitate the performance of health behaviours, which is solidly established in the academic community (House, Landis & Umberson, 1988). Previous studies have found that the more social support a person has the less *emotional barriers* they have, the more inclined they are to copy positive health behaviours, and the success rate of these new practices is higher (Komproe et al., 1997). In the particular context of this study, higher social support can lead to better adherence of individuals to breast cancer screening guidelines and to increase the number of breast self-examinations (Katapodi et al., 2002, Griep & Rotenberg, 2009). Thus, to successfully boost women's adoption of positive

health behaviours it is crucial to understand the influence that the social environment has on them.

The impact of social support and social constraints on an individual can be analysed by using the *degree of collectivism*, which refers to the intensity from society on individuals to take care of others. Hence, a high degree of collectivism can result in more intensive social support and constraints, which is especially prevalent in cultures with origin in non-western European societies (Minkov & Hofstede, 2010). When talking about individual's own behaviours the word *altruism* is used, which is the helping of others without expecting something in return. Here, individuals who are high altruistic are more likely to practise health behaviours that they consider to be beneficial for their social environment (Brown, Consedine, & Magai, 2005). An example in this study's context, is that individuals with high altruistic behaviours share their own cancer experience with others more openly to motivate them to practice the same health behaviours (Scarinci et al., 2012). Additionally, very often high altruistic individuals get their own health information from their own social environment (Ersin & Bahar, 2011). Hence, they share their experiences regarding health more openly, but also listen to other individuals for information. Thus, it can be assumed that health promotion lies partly on the shoulders of the social environment (see Berkman, 1995).

Besides social support and constraints, the social environment can also provide a *role model*, which can help increase women's participation in a mammography (Lee-Lin et al., 2007). Role models are a part of self-efficacy, where the individual learns a new health behaviour from someone who has already adopted it and with whom they have a positive relationship (Bandura, 1997). Their perceptive on their own competences to adopt a health behaviour is thus increased as the role model is an example for them.

In a nutshell, a person's social environment can influence their willingness to participate in a breast cancer screening through their social support, social constrain, degree of altruism, and the availability of a role model.

### **Cultural Factors and Breast Cancer Screening**

A wide variety of cultural factors can influence an individual's health behaviour. On the subject of breast cancer screening the main factors are clustered in three different groups: health literacy, language proficiency and communication, and healthcare experience and emotional barriers. Together they are often referred to as the *triple threat* in health accessibility and prevention (Schyve, 2007). While they are all discussed separately, it is thus vital to understand

that the three groups work together in supporting or opposing the accessibility of breast cancer screening.

### **Health Literacy**

Recently, health providers and behavioural scientists' have moved their attention to *health literacy*, which is the increase of knowledge about health-related causes. It also deals with the change in attitudes, motivation, personal skills, and self-efficacy regarding good health. Important for this study is that high health literacy skills gives individuals the ability to understand a disease (*basic literacy*), the tools to gain knowledge about that disease (*communicative literacy*), and to communicate as well as critically reflect upon specific medical diagnoses (*critical literacy*) (Freebody & Luke, 1990). Thus, health literacy is not limited to the knowledge of medical definitions, but also to the individuals' empowerment when facing a medical diagnosis (Nutbeam, 1998).

There are disparities in health literacy among ethnic groups, where specifically non-white elderly and individuals with a migration background show lower health literacy skills, causing them to have more misconceptions and to be less informed about their diagnoses (Gansler et al., 2005; van der Heide et al., 2013). A systematic review of 36 studies also found that to reduce health disparities between ethnic groups the focus should be on increasing their health literacy (Mantwill, Monestel-Umaña & Schulz, 2015), as it can limit the effects of social constraints from their social environment (Schmidt & Andrykowski, 2004).

Research in oncology and health literacy determined that individuals with low health literacy skills are more likely to experience a delay in follow-up testing (Yabroff et al., 2004), have less ability to evaluate online health information (Diviani et al., 2015), and have more misconceptions about cancer resulting in unnecessary treatments and medical interventions (Koay, Schofield & Jefford, 2012). Specifically, on breast cancer screenings, scholars agree that women with lower health literacy tend to participate in fewer mammographies or even none at all (Berkman et al., 2011). It is thus vital for the individuals' health, as well as for healthcare providers, that they have a certain level of health literacy.

### **Language Proficiency & Communication**

A person's proficiency in the national language(s) of the country where they reside can linked to their ability to received adequate healthcare, as it can influence their health literacy as well as their communication with health professionals (Jacobs et al., 2005). The latter is affected by the person's communication norms, locus of control, and social environment (Singleton &

Krause, 2009). In the field of oncology, individuals who have low language proficiency show more difficulties in understanding the purpose of cancer screenings and symptoms of their diagnoses. This directly influences the communication and discussion with the health professionals as well as their informed consent to medical treatments (Davis et al., 2002). Additionally, studies on breast cancer screenings show that lower language proficiency and poor health communication impact an individual's health-seeking behaviour which by extension affects the rate of participation in mammographies (Cummings, Jette & Rosenstock, 1987; see Kristiansen et al., 2016).

In the context of the Netherlands, a recent research found that for patients with Turkish and Moroccan cultural heritage the most common factors for nonparticipating in cancer research were difficulties with patient-doctor communication due to low language proficiency, health literacy skills, and limited knowledge of the family cancer history (Baars et al., 2017). Similar findings were obtained in another Dutch research on colorectal cancer among ethnic minority groups, which showed that lower health literacy, low levels of self-efficacy, and low language proficiency caused serious barriers to informed participation in screenings (Woudstra et al., 2016). Thus, improving individuals' language proficiency skills, their communication with healthcare professionals, and their health literacy skills can directly impact and increase the breast cancer screening participation in The Netherlands.

### **Healthcare Experience and Emotional Barriers**

A situation that can negatively affect patient's participation in cancer screenings arises when healthcare organisations are *cultural insensitive*, which causes individuals to develop mistrust and negative perspectives towards them (Hong, Tauscher & Cardel, 2018; Zanchetta & Poureslami, 2006). Additionally, these negatives experiences create emotional barriers, specially when combined with *anxiety-driven cultural perception* (Sarma, 2015). An example of this in the context of breast cancer screenings could be when a patient perceives disrespect from screening providers. Situations like this ultimately lead to lower participation in such tests from individuals with diverse cultural and linguistic background (O'Hara et al., 2018). To decrease emotional barriers, negative experiences need to be limited, while the increase of social support will mitigate anxiety-driven cultural perceptions (Komproe et al., 1997).

The advocacy for culturally sensitive healthcare is backed up by previous studies which showed that specific health promotions designed to match the individual's cultural factors, religious values, group identity, and language proficiency can limit negative experience and ultimately eliminate health disparities (Thomas, Fine, and Ibrahim, 2004). Similarly, a

recent comparative research among newly arrived migrants in seven European countries found that they faced linguistic and cultural barriers in healthcare promotion, which could be overcome with compassionate and culturally sensitive approaches from health professionals as well as more information on medical procedures (van Loenen et al., 2018). It thus becomes evident that negative experience, anxiety-driven cultural perceptions towards healthcare, and cultural insensitive healthcare professionals can lead to a decreased participation in breast cancer screening.

## Research Question

Empirical studies have shown that to limit the mortality rate of breast cancer, early detection is crucial. Breast cancer screenings in the form of a mammography is one of the most popular and recommended tools among health professionals for the early detection of this disease. However, due to health disparities, not everyone has equal possibilities to participate in this health procedure. Current literature provides us with evidence that the individual's health literacy, language proficiency, experiences with healthcare, cultural perceptions, and their social environment can create barriers in accessing breast cancer screening. This research focusses on identifying these barriers among both the high-risk and non-high-risk non-Dutch mother tongue speaking women living in the Netherlands, where the non-high-risk women also function as the social environment for the high-risk women.

To gain a better understanding of why in particular these women perceive different barriers, an explorative pilot study is required. In this way, it can be assessed how (future) communication concerning breast cancer screening can be adapted for them in a way that they perceived as positive. By focussing on a wide variety of cultural factors, this pilot study provides the first clues into are the effects of different cultural factors on breast cancer screening participation. Additionally, this pilot study provides a foundation for future research on the accessibility of breast cancer screening, and, ultimately, help increase early detection and lower mortality rate of breast cancer.

This study answers the main research question: *How are health literacy, cultural perception, and past experiences of non-Dutch mother tongue speaking high-risk women and their social environment related to accessing breast cancer screening?* The research question is divided up in two sub-questions: *How are health literacy, cultural perceptions, and past experiences related to accessing breast cancer screening amongst non-Dutch mother tongue speaking high-risk women?* and *what are the health literacies, attitudes, and past experiences of the social environments towards breast cancer screening?* The data to answers these research questions was collected by conducting self-administered digital questionnaires containing closed and open-ended questions for both the high-risk individuals as well as their social environment.

## Methods

The presented community-based pilot study aimed at giving new insights into the cultural factors influencing the accessibility of breast cancer screening, but also to test the feasibility of the chosen tools, methods, and approaches. The study is a quantitative study with rich multi-level analyses of the data through descriptive and inferential statistical analyses of the closed-ended questions and a quantitative content analyses of the open-ended questions.

### Community-Based Research

This pilot study is based on the discourse of *community-based research* (CBR) which means that the study is established in collaboration with the target population, in this case, the Mammarosa Foundation. By using CBR, the researcher was able to use *social inquiry* (in-depth knowledge from practical experience) of Mammarosa Foundation as well as create a study that has *real-life application* (Maurrasse, 2002). The community-based approach has affected not only the establishment of the research question but also the tool, the translations, the distribution, and an assessment of which recommendation are feasible. By doing so, it limits the negative aspects of the quantitative nature of this study, such as the aggregation and categorisation of data (Hulme, 2007). In addition, the use of CBR in a pilot study is particularly important as the collaboration with the community leads to findings results more successfully (Bacon, 2003; Ohmer & Korr, 2006; Ohmer et al., 2013). Ultimately, by achieving social justice for the barriers in breast cancer screening, CBR leads to the closing of the highly criticised gap between academia and communities.

The basis of this CBR was the collaboration with non-Dutch mother tongue speaking women, which are represented in this study by Mammarosa Foundation. They are a small-scale volunteer organisation located mainly in the *Randstad* (an urban agglomeration of the bigger cities in mid-west Netherlands), who provide information, support, and guidance to non-Dutch mother tongue speaking and low-literacy women on breast cancer. As Mammarosa Foundation is embedded into the community, they are the perfect organisation to collaborate with. For them, a CBR provides the possibility to answering prominent questions without them needing to have the financial resources to facilitate the needed research (see Bacon, 2003).

## Participants

The participants for the questionnaire were women who do not solely identify as being Dutch and who are living in the Netherlands. In total, 40 participants filled in the questionnaire; however, two of them were removed as one did not live in the Netherlands and the other identified as only Dutch. Of the leftover 38 participants, only 2 participants belonged to the high-risk group (50-75 years old), due to this small number the data could *not* be used for analyses on this group. However, due to an extensive overview of previous empirical studies, a conceptual diagram is presented that visualized the direct and indirect variables that influence participation of high-risk women in breast cancer screening. The argumentation, as well as the impact of this removed, is given in the discussion section. Thus, in total, the analysed sample consisted of only 36 responses who are all non-Dutch mother tongue speakers and function as the social environment of the high-risk women.

The participants mean age is 33.3, with the youngest being 23 and the oldest 49 years. The sample has a diverse cultural heritage, with Latin American (compiled out of Dominican Republic ( $n = 2$ ), Venezuela ( $n = 7$ ), and Chile ( $n = 1$ ) being the biggest, followed by Turkish ( $n = 8$ ) (see table 1). Regarding the religion of the participants, not religious is the most prominent group (see table 2). The participants' residential location was spread around the country; however, the *Randstad* is predominantly represented (see image 1).

It is crucial to highlight here that due to the small sample as well as the critical perspective on essentialist approach to culture, the results cannot be used to generalize about specific cultural groups or about the whole target population. This includes the limitation to assess systematic exclusion or discrimination of specific cultural heritage groups. Instead it should be used to provide a bird eye perspective on possible cultural factors that influence health behaviour.

Table 1

### *Cultural heritage of participants*

Cultural Heritage groups	<i>n</i>
Turkish	8
Latin American	10
West European	6
East European	3
South European	2
Moroccan	2
Others	5

Table 2

### *Religious group of participants*

Religion	<i>n</i>
Christian	11
Muslim	9
Not religious	14
Missing	2



Image 1

*Residential location of participants***Instruments**

The questionnaire consisted out of a total of 37 questions, among them being 31 closed questions and six open ended questions (see appendix 1 - questionnaire). They identify past experiences, health literacy, and cultural health belief factors regarding breast cancer screenings. To make the questionnaire suitable for a broad audience, with individuals who have low literacy skills and low language proficiency skills, the complexity of sentences and word use was lowered by adhering to the *Guidelines for Easy Language* (Alliantie gezondheidsvaardigheden, 2013), and *Easy Language for Low Literacy Individuals* (Stichting Lezen & Schrijven, 2017). In addition, to assess the accessibility for non-Dutch native speakers the questionnaire was sent to one person with level Dutch A2 (mother tongue Cantonese and English) and one Dutch B1 level person (mother tongue Spanish and German). Their feedback was incorporated in the final version.

Together with Mammarosa Foundation a digital self-administered questionnaire was chosen, which has three advantages: firstly, by conducting the questionnaire digitally, it is easier to reach a broad audience quicker and cheaper than physical or oral questionnaires.

Especially in the period the study was conducted, which was during the COVID-19 pandemic, a digital questionnaire offered the possibility to still reach individuals without the risk of causing excessive harm to the participants. Secondly, by choosing self-administered the *interviewers' effect* is limited, which is biased in answering because of the interviewer's ethnicity, gender and social background (commonly due to the tendency for people to be exhibiting social desirability). Thirdly, due to the possible sensitivity of the research topic, having the convenience for responders to answer the questions in their own time and at their preferred setting provides more authentic answers (Bryman, 2016). However, this type of questionnaire does have the downsides of having a lower response rate, as well as not providing respondents with the chance of asking the researcher about confusions with specific questions (Bryman, 2016). In addition, the concern that individuals with low digital literacy skills experience inaccessibility is prominent.

For the software, the program Qualtrics was used, as it assures a well-functioning digital surrounding on both mobile and laptop use, ensures the privacy of participants, and allows for multiple translations. In the end, the participants on average took 879 seconds (14.6 minutes) to complete the questionnaire. However, there was a big difference in the duration for completion between the quickest participants with 304 seconds (5 minutes) and the longest with 1523 seconds (25 minutes). The differences can be explained due to the possibility in Qualtrics to pause the answering of the questionnaire.

### **Translations**

Together with Mammarosa Foundation it was decided to have the questionnaire provided in five languages: Dutch, English, Arabic (standardised), Turkish and French. The first two were created and translated by the researcher themselves, while the latest three were provided by external individuals who have the language as their mother tongue and who have a background in health or social science. To assure accuracy, the translations were thoroughly checked by other native speakers. However, cultural adaptations that diverge from the original questionnaire (Dutch and English variation) are limited, as the current study is not capable of reviewing the suitability and validity of specific cultural adaptations.

The choice of which language was decided based on the most prominent non-western language community in the Netherlands which are Turkish, Moroccan (predominantly Berber and a small group French), and Suriname (predominantly Dutch and a small group Sranantongo) (CBS, 2020). The original plan was to have the questionnaire translated to Berber (Tamazight), but unfortunately, there was not a translator available; thus, the decision was

made to translate the questionnaire to French instead. In the end, the participants used the following translations: two times Arabic, one time French, 20 times English, and 13 times Dutch. Turkish was not used, even though eight participants identified as having a Turkish heritage.

### **Scale**

The questionnaire is based on two different indexes, adaptation of the *Cultural Assessment Framework* (CAF) as provided by Huff and Kline (2014) and the adoption of *the Single-Item Literacy Screening* (SILS) as provided Kelly et al. (2018).

CAF offers a systemic approach to the understanding of similarities and difference in cultural health beliefs and practices between diverse individuals. The adaptation of this index in the questionnaire consisted out of the following sections: demographic characteristics (gender, residence and background); perception of morbidity and mortality in regards to breast cancer; general cultural characteristics (norms, values and customs); and, general health characteristics (perception on the healthcare system and experiences).

The SILS is a simple screening which evaluates an individual's health literacy, by using only three questions (education level, reading and filling in medical documents) it provides a first insight into the participants' health literacy without causing too many disturbances. The questionnaire has proven to have strong reliability and validity (Cordasco et al., 2012). Both indexes have been successfully used in variety of communities by different researchers. However, SILS has its limitation due to its narrow analysis of health literacy, which causes its psychometric properties to be under discussion (Jordan, Osborne & Buchbinder, 2011). In this study it was decided to not use SILS as a tool to define health literacy completely, but instead to assess their reading comprehension of health information.

Furthermore, it is crucial to recognize that the data collection happened during the COVID-19 pandemic. In the Netherlands, the COVID-19 pandemic led to an intelligent lockdown of all non-essential work and a forcefully suggestion by the government to stay at home. It is highly likely that this increased emotional distress among participants as well as willingness and availability to participate in this study, creating possible skewed answers.

### **Distribution**

The distribution of the questionnaire was done with the so-called *snowball sampling*, which means that the participants who first receive the questionnaire are motivated to forwards the

questionnaire to others (see appendix 1 – introduction). The data collection took 26 days, from the 5th of May until the 31st of May 2020. The questionnaire was distributed through a post in both English and Dutch on the LinkedIn of the researcher as well as the LinkedIn from a Mammarsosa board member. The post of the study, in the end, had the following engagement reach: 41 'likes', three comments, four shares, and 1030 views. While the post of the board member on LinkedIn had in total an engagement reaches of 3 'likes', four comments, and 180 views. The use of LinkedIn had a direct influence on who was reached, as it is a social media platform mainly used by professionals who want to extend their work-related network.

### **Analyses Closed-Ended Answers**

The closed ended answered were analysed through both descriptive and inferential statistics. The descriptive provided an overview of the participant's answers and served as a tool to separate them into different categories derived from the literature and the research question. In addition, due the pilot nature of this study, the descriptive were also used to determine the inferential tests, where intriguing findings in the descriptive were analysed further to observe if there are significant differences between variables. In total 12 different hypotheses and correlating test were created and executed, which are explained in the results together with their quality and suitability.

For the analyses, the Statistical Package for Social Sciences for Windows (SPSS) 26th edition was used. The two questions on the conversations with the general practitioner (GP) showed to have measured the same construct, as the scale had a high-level consistency determined by a Cronbach's alpha of 0.872. Thus, these two questions were merged into a mean of both questions. The data does not contain other high or medium level consistent variables that could be merged, which is specifically surprising for the five question on breast cancer screening knowledge ( $\alpha = .496$ ) and the SILS questions ( $\alpha = .521$ ). Also, inter-item correlation did not provide a possible combination with an acceptable consistency ( $\alpha = .7>$ ).

### **Analyses Open-Ended Answers**

Three open-ended answers of the questionnaire were analysed descriptively using *quantitative content analysis*, which is the highlighting of reoccurring patterns (codes) of meaning in the answers and the quantifying of these patterns (Holsti, 1969, p.14). In this study, it provided more in-depth insight into the participants own experience, perception, and recommendation for motivating non-Dutch mother tongue speaking women to participate in breast cancer

screening. As all the open-question answers were either in Dutch or English, there was no need for translations. The themes were established inductively, meaning that they were drawn from the given answers by the researchers using the computer assistant software program NVivo 12.6 pro (see appendix 2 – coding manual).

The use of open-ended questions with content analysis can provide more in-depth information on the participant's perception and it lets the participant have a certain degree of freedom in expressing their answer (Boruchovitch & Schall, 1999). The advantages of in this study are the flexibility and transparency as well as the extension upon the answers found in the closed questions. However, the downside is that there is a possible of bias in coding by the interpreter (Bryman, 2016). As a measure to prevent the *interpreter bias*, an external auditor was asked to observe if the codes correctly analysed quantitative patterns in the open-ended questions. They did not find any cases of disagreement, which enhances the inter-coder reliability and thus the comprehension and validity of the results (see Cavanagh, 1997).

## Results

In this results section, the descriptive of the closed question are presented with both the characteristics of the whole sample and of different groups. Based on visible findings, twelve hypotheses with correlating inferential are executed. Finally, the quantitative content analysis of the three open questions are presented.

### Descriptive Statistics

#### Information Sample

The participants' Dutch language proficiency is diverse, with the median being B2 level and the mode with 30.6% is C2 level (native proficiency) (see table 3). Regarding their education, 34 of the 35 participants have achieved more than 13 years of education, which in practice entails that they participated in post-secondary education (see table 4). The participants were also asked about their own experience with mammographies, 27.8% answered that they have participated in having a mammography (see table 5).

Table 3

*Language proficiency*

	<i>n (%)</i>
No Dutch	4 (11.1)
A level	7 (19.4)
B1 level	5 (13.9)
B2 level	5 (13.9)
C1 level	4 (11.1)
C2 level	11 (30.6)
Total	36 (100)

Table 4

*Education level*

	<i>n (%)</i>
7-12 years	1 (2.9)
13+ years	34 (97.1)
Missing	1 (-)
Total	36 (100)

Table 5

*Experience with mammography*

	<i>n (%)</i>
Yes	10 (27.8)
No	26 (72.2)
Total	36 (100)

#### Knowledge on Breast Cancer Screenings

To gain insights into the participants' knowledge on breast cancer, five knowledge questions (KQ) were asked regarding facts on susceptibility, screening, and treatments. On the first KQ of 'one in every seven women in the Netherlands will get breast cancer' the majority (n=29) said they did not know about the susceptibility of breast cancer. Similar lack of knowledge was found with KQ 5 'treatments available for breast cancer', where 69.4% of the participants did not know which treatments against breast cancer are available. Answers on KQ 3 showed a 50/50 distribution, where half of the participants were aware that there are free breast cancer

screenings ever two years, while the other half did not. For KQ 2 (50-75-year-old women are high risk) and KQ 4 (what is mammography) most of the participants answered that they did know these (see table 6).

To understand if there are differences in knowledge between participants, the answers were separated into the group's migration background and Dutch language proficiency. Based on the table below (see table 7), it is visible that participants with a high proficiency are more aware of the perceptibility (KQ 1) in comparison to individuals with low language proficiency. Other combinations do not show any clear visible increase or difference between groups.

Table 6

*Answers knowledge questions all participants*

	KQ 1 <i>1 in 7 women</i>	KQ 2 <i>50-75 high risk</i>	KQ 3 <i>Free Screening</i>	KQ 4 <i>Mammography</i>	KQ 5 <i>Treatment</i>
	Frequency (%)				
Yes	7 (19.4)	24 (66.7)	17 (47.2)	34 (94.4)	11 (30.6)
No	29 (80.6)	12 (33.3)	19 (52.8)	2 (5.6)	25 (69.4)

Table 7

*Answers knowledge questions separated on migration background and language proficiency*

	KQ 1 <i>1 in 7 women</i>		KQ 2 <i>50-75 risk</i>		KQ 3 <i>Free Screening</i>		KQ 4 <i>Mammography</i>		KQ 5 <i>Treatment</i>		
	<i>n</i>	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Migration background %											
1e generation	15	13	87	67	33	33	67	100	-	27	73
2e generation	8	37.5	62.5	75	25	75	25	75	25	37.5	62.5
3th generation	2	50	50	50	50	50	50	100	-	50	50
No migration	10	10	90	70	30	50	50	100	-	30	70
Missing	1										
Language proficiency %											
No Dutch	4	-	100	25	75	25	75	100	-	-	100
A level	7	14	86	57	43	57	43	100	-	43	57
B1 level	5	20	80	80	20	40	60	100	-	-	100
B2 level	5	-	100	80	20	40	60	100	-	20	80
C1 level	4	25	75	75	25	25	75	100	-	50	50
C2 level	11	36	64	73	27	64	36	82	18	45	55

### Health Literacy

Besides the education background, the two SILS questions were asked to measure the participants' health literacy skills, more specifically their reading comprehension skills; where the closer the number is to one the higher the health literacy skill. The median of SILS 1 shows

that participants are *somewhat confident* with filling in medical forms, and the median of SILS 2 shows that they finding it *sometimes difficult* to read writing information on their health (see table 8).

The two SILS questions are also measured in three different groups: the participants' own experience with mammography, their family's experience with mammography, and their family's experience with breast cancer. This could show how previous experiences with breast cancer (screening) can influence the participants' health literacy skills. However it becomes visible that both SILS questions do not show an apparent increase or decreases, meaning that there is no a visible relationship between experience with breast cancer and both health literacy domains (see table 9)

Separating the participants on migration background and Dutch language proficiency also show that there is no visible difference in health literacy based on migration background. However, there is a visible difference based on language proficiency (table 9). Participants who have a higher language proficiency show a higher health literacy in those two domains in comparison to lower language proficiency, this is especially clear with SILS 2.

Table 8

*Answers single-item literacies all participants*

	Single-item literacy 1 <i>Confidence with filling in medical forms</i>	Single-item literacy 2 <i>Reading written information about their health</i>
<i>n</i>	31	33
<i>Mean</i>	2.58	2.82
<i>Median</i>	2	3
<i>SD</i>	.807	1.074
<i>Missing</i>	5	3



Table 9

*Answers single-item literacies separated in groups*

		Single-item literacy 1	Single-item literacy 2
	<i>n</i>	<i>Mean</i>	<i>Mean</i>
Mammography - self			
Yes	9	2,56	3
No	20	2,6	2,7
Missing	7		
Mammography - family			
Yes	19	2,58	2,58
No	7	2,43	3,57
Missing	10		
Breast cancer - family			
Yes	12	2,5	2,25
No	14	2,57	3,36
Missing	10		
Migration background			
1e generation	12	2,42	3
2e generation	7	2,86	1,86
3th generation	2	2	3
No migration	8	2,75	3,25
Missing	7		
Language proficiency			
No Dutch	2	2,5	2,5
A level	3	2,67	3
B1 level	5	2,4	3,8
B2 level	5	3	3
C1 level	4	2,25	2,75
C2 level	9	2	2,2
Missing	8		

### Dutch Healthcare

The following descriptive are on the participants' communication with their General Practitioner (GP), as well as their perception on and experience with the Dutch healthcare. Regarding perception, 50% of the participants say that they perceive obstacles (negative perception) in obtaining good healthcare in the Netherlands. For the experience, both positive and mixed experiences are 34.5% and negative experience is at 25%. And overall, the participants find their conversations with their GP between *always* and *often* understandable, meaning that the participants can understand the GP and they feel that the GP understands them (see table 10).

When comparing the participants based on their Dutch language proficiency, participants with high proficiency rate their conversations with the GP higher and they have less negative experience with Dutch healthcare in. However, they do perceive more obstacles (negative perception) in accessing good healthcare. When separating the group on migration generation, there is no clear visible difference between the generations. Interesting is the difference between participants who participated before in a mammography and those who have not. Individuals who had a mammography face more barriers in accessing good healthcare (negative perception), have more mixed and less positive experiences with Dutch healthcare, and have better understandable conversations with their GP in comparison to participants who have not had a mammography (see table 11).

Table 10

*Answers healthcare all participants*

	<i>n (%)</i>	<i>Mean (SD)</i>
Perception of healthcare		
Positive (no obstacles)	17 (50)	
Negative (obstacles)	17 (50)	
Missing	2	
Experience with healthcare		
Positive	11 (35.5)	
Negative	9 (25)	
Mixed	11 (35.5)	
Missing	5	
Communication with GP		
		1.4 (.55)

Table 11

*Answers healthcare separated in groups*

	<i>n</i>	Perception of healthcare		Experience with healthcare			Communication with GP
		Negative %	Positive %	Positive %	Negative %	Mixed %	<i>Mean (SD)</i>
Language proficiency							
No Dutch	3	66.6	33.3	33.3	66.6	-	-
A level	6	66.6	33.3	16.6	50	33.3	2 (.79)
B1 level	5	80	20	20	40	40	1.3 (.44)
B2 level	5	43	57	40	40	20	1.7 (.44)
C1 level	3	0	100	66.6	-	33.3	1.33 (.57)
C2 level	11	36.3	63.7	44.4	-	56.4	1.056(.17)
Missing	3						

		Migration generation					
1e generation	14 50	50	47	30	23	1.75 (.66)	
2e generation	8 37.5	62.5	50	-	50	1 (0)	
3th generation	2 -	100	50	-	50	1 (0)	
No migration	8 67	33	11.1	44.4	44.4	1.44 (.42)	
Missing	4						
		Mammography - self					
Mammography	9 44.4	65.6	11.1	22.2	66.7	1.27 (.44)	
No Mammography	22 52	48	45.5	31.8	22.7	1.55 (.6)	
Missing	5						

### Inferential Statistics

Based on the descriptive statistics, it can be assumed that in this sample, there were no differences based on the participants religious believes and migration background. However, there were visible differences based on the participants' language proficiency and whether they had a mammography themselves. On these findings, twelve hypotheses with correlating inferential tests were constructed (see appendix 3 – analysis scheme). To ensure that no assumptions of the tests were violated, preliminary checks were executed (sample size, normality, and multicollinearity). The argumentation of each test is rather extensive as it provides evidence of the validity of the results themselves, making it a vital part of a quantitative study (Norris et al., 2015). In all tests, the groups showed independence of observation, and the differences were considered significant at level  $p = .05$ .

To properly assess the impact of Dutch language proficiency, it was decided to group the six different levels into two groups, *Low Language Proficiency* (LLP) and *High Language Proficiency* (HLP), where the LLP individuals have level No Dutch to B1 and HLP individuals have level B2 to C2 (see Fasoglio & Tuin, 2018). However, four additional tests with language proficiencies as ordinal were also executed, these can be found in appendix 3.

### Hypotheses 1 to 3

For hypothesis 1, the difference between the individuals' proportion of knowledge on breast cancer (dichotomous variable) and language proficiency (dichotomous variable) was tested using null hypothesis (H0): *The difference between the proportion of knowledge on breast cancer in the participants who have a low Dutch language proficiency and those with high Dutch language proficiency is equal.* For KQ 1, 4 and 5 the Fisher's exact test was run as the expected cell frequencies were not greater than five, for KQ 2 and 3 a chi-square test of homogeneity was used as they did fulfilled this requirement (see appendix 3 – analyses

scheme). All assumptions regarding binominal proportions were met. The groups consisted out of 16 low Dutch language proficient (LLP) individuals and 20 high Dutch proficient (HLP) individuals. The five knowledge questions were all tests individually as they had a low internal consistency ( $\alpha = .496$ ).

The tests show that HLP individuals' have a higher proportion of knowledge on KQ1, KQ2, KQ3, and KQ5 than LLP individuals, however on KQ4 the reversed is found (see table 12). Nonetheless, none of the differences in proportion of the five-knowledge question were found significant (see table 12) meaning that the proportion of knowledge between LLPs and HLPs are equal and the H0 must be accepted.

Table 12

*Chi-Square of homogeneity and Fisher's exact test on language proficiency and knowledge questions*

	KQ 1		KQ 2		KQ 3		KQ 4		KQ5	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Low language proficiency										
Count	2	14	9	7	7	9	16		3	13
Expected Count	3.1	12.9	10.7	5.3	7.6	8.4	15.1	0.9	4.9	11.1
% within language group	12.5	87.5	56.3	43.8	43.8	56.3	100		18.8	81.3
High language proficiency										
Count	5	15	15	5	10	10	18	2	8	12
Expected Count	3.9	16.1	13.3	6.7	9.4	10.6	18.9	1.1	6.1	13.9
% within language group	25	75	75	25	50	50	90	10	40	60
Chi-Square of homogeneity and Fisher's exact test results										
<i>df</i>	1		1		1		1		1	
<i>N</i>	36		36		36		36		36	
<i>X</i> <sup>2</sup>			1.406		.139					
<i>z</i>	.125		.198		.063		.1		.198	
<i>p</i>	.426		.236		.709		.492		.277	

For the second hypothesis, the difference in proportion of communication with family members (dichotomous variable) between the two language proficiency groups (dichotomous variable) were tested with the H0: *The difference between the proportion of communication with family about breast cancer in the participants who have a low Dutch language proficiency and those with high Dutch language proficiency is equal.* All assumptions regarding binominal proportions were met, but the expected cell frequencies were not greater than five, thus the Fisher's exact test was executed (see table 13). The groups consisted out of 16 LLPs and 18

HLPs. The tests results showed at conclusion that individuals with LLP (12.5%) communicate less about breast cancer with family compared to individuals with HLP (22.2%), however this difference was insignificant and the H0 must be excepted, (1,  $N = 34$ ),  $z = .099$ ,  $p = .66$ .

The third hypothesis assed the significance of difference in proportion of perception on accessibility of healthcare (dichotomous variable) between the two language proficiency groups (dichotomous variable) with H0: *The difference between the proportion of perception on Dutch healthcare accessibility in the participants who have a low Dutch language proficiency and those with high Dutch language proficiency is equal.* All assumptions regarding binominal proportions were met and the expected cell frequencies were greater than five, thus the Chi-Square of homogeneity was executed (see table 13). The groups consisted out of 14 LLPs and 20 HLPs. The tests results showed at conclusion that LLP individuals (28.6%) have a lower proportion of negative perception compared to HLP individuals (65%), this difference was also found significant,  $X^2 (1, N = 34) = 4.371$ ,  $z = .364$ ,  $p = .037$ . Thus, the H0 can be rejected, and it can be assumed that HLP individuals in this sample have more negative perceptions on the accessibility of Dutch healthcare.

Table 13

*Chi-Square of homogeneity and Fisher's exact test on language proficiency and both communication with GP and perception on healthcare*

	Communication family		Perception on healthcare	
	Yes	No	Positive	Negative
Low language proficiency				
Count	14	2	10	4
Expected Count	13.2	2.8	7	7
% within language group	87.5	12.5	71.4	28.6
High language proficiency				
Count	14	4	7	13
Expected Count	14.8	3.2	10	10
% within language group	77.8	22.2	35	65

#### **Hypotheses 4 to 6**

Hypotheses 4 to 6 compared both SILS, experience with Dutch healthcare, and communication with GP (all ordinal variables) with the two language proficiency groups (dichotomous variable). While there were no visible outliers in the boxplots (see appendix 3- boxplots) and the variances were homogeneous (as assessed by Levene's test for equality of variances,  $p = 0.05$ ), the parametric t-test could not be used as the dependent scores for the lower proficiency were not normally distributed (as assessed by Shapiro Wilk test,  $p = <.05$ ). Thus, Mann

Whitney  $U$  tests were used. The distribution for both health literacies scores as well as for the experiences with healthcare were not similar, as assessed by visual inspection (see appendix 3 - boxplots). However, the distribution for communication with the GP was equal. For all  $H_0$ , the significance was measured using the exact sampling distribution for  $U$  (Dineen & Blakesley, 1973).

For hypothesis 4 on experience with health used the  $H_0$ : *The distribution of experience with Dutch healthcare for the two language proficiency groups are equal.* The difference in experience with Dutch healthcare between low LLPs (mean rank = 19.64) was significantly higher than the one of the HLPs (mean rank = 13),  $U = 68$ ,  $z = -2.149$ ,  $p = .044$ . Meaning that it can be assumed that individuals in the sample with HLP have more positive experience with healthcare than LLPs.

Hypothesis 5 on SILS used  $H_0$ : *The distribution of both health literacies scores for the two language proficiency groups are equal.* The test determined that SILS 1 score for LLPs (mean rank = 16.32) was higher than the one of the HLPs (mean rank = 15.83). However, the difference was not statistically significant,  $U = 106.5$ ,  $z = -.155$ ,  $p = .887$ . The same was found for the distribution for SLIS 2 between LLPs (mean rank = 20.21) and HLPs (mean rank = 14.63),  $U = 88$ ,  $z = -1.699$ ,  $p = .106$ . Thus, it cannot be assumed that LLP individuals in this sample have lower health literacies scores in the two domains.

The hypothesis 6 on difference in a communication with GP score, had as  $H_0$ : *The mean ranks of communication with GP scores for the two language proficiency groups are equal.* Here the median could be used due to similar distribution between the two groups. The Mann-Whitney  $U$  test determined that while the communication with GP was less understandable among LLPs compared to HLPs (see table 14), this difference was not significant,  $U = 78.5$ ,  $z = -1.618$ ,  $p = .152$ . Thus, the null hypothesis must be accepted.

Table 14

*Mann-Whitney  $U$  test on language proficiency and communication with GP*

	Communication with GP
	<i>Mdn</i>
LLP	1,5
HLP	1
Total	1

### Hypothesis 7 to 9

To determine if there was a difference in language proficiency, perception on accessibility of healthcare, and the communication about breast cancer with their family (all dichotomous variables) on the basis if the individual had a mammography themselves or not (dichotomous variables), three Fisher's exact test were executed. While the assumptions regarding binomial proportions were met, not all expected cell frequencies were higher than five.

The H0 of hypothesis 7 on mammography and language proficiency was: *The difference between the proportion of language proficiency in the two groups of mammography is equal to 0*. The test concluded that of the participants who had a mammography 55.6% had high language proficiency, compared to 48% of those that did not have a mammography. However, this difference in proportion was insignificant, (1,  $N = 36$ ),  $z = .062$ ,  $p = 1.0$  (see table 15).

Also, hypothesis 8 with H0: *the difference between the proportion of perception of Dutch healthcare in the two groups of mammography is equal*, showed an insignificant difference between participants who had a mammography and negative perception (55.6%) compared to those that did not have a mammography (48%), (1,  $N = 34$ ),  $z = .072$ ,  $p = 1.0$  (see table 15).

Furthermore, hypothesis 9 on communication with family and mammography groups with H0: *The difference between the proportion of communication about breast cancer with family members in the two groups of mammography is equal*, had an insignificant difference in proportions between participants who had a mammography and talk about breast cancer with their family (20%) compared to those who have not had a mammography (16.7%) (1,  $N = 34$ ),  $z = .033$ ,  $p = 1.0$  (see table 15).

It thus can be assumed that there are no differences in proportion between the two mammography groups regarding their language proficiencies, perception on Dutch healthcare, and communication with their family members about breast cancer.

Table 15

*Fisher's exact test on mammography and language proficiency, perception on healthcare and communication with family members*

	Language proficiency		Perception on accessibility healthcare		Communication with family members	
	Low	High	Positive	Negative	Yes	No
Participants who had a mammography						
Count	4	6	4	5	8	2
Expected Count	4.4	5.6	4.5	4.5	8.2	1.8
% within language group	40	60	44.4	55.6	80	20
Participants who did not have a mammography						
Count	12	14	13	12	20	4
Expected Count	11.6	14.4	12.5	12.5	19.8	4.2
% within language group	46.2	53.8	35	52	48	16.7

### Hypotheses 10 to 12

The last three hypothesis determine if there is a difference with experience with Dutch healthcare, communication with GP, and both SILS (all ordinal variables) between the mammography groups (dichotomous variable). While they did not show any visible outliers, the parametric t-test could not be used as all dependent group scores were not normally distributed as assessed by Shapiro Wilk test ( $p < .05$ ). The distribution for the health literacies scores was not equal, as assessed by visual inspection (see appendix 3 - boxplots). However, the distribution for communication with GP and experience with Dutch healthcare were similar. For all null hypotheses, the significance was measured using the exact sampling distribution for  $U$  (Dineen & Blakesley, 1973).

Hypotheses 10 on the difference in a communication with GP used  $H_0$ : *The mean ranks of experience with Dutch healthcare scores for the two mammography groups are equal.* The Mann-Whitney  $U$  test determined that both the participants who have participated in a mammography and those who had not rate the communication with GP the similar (see table 16),  $U = 113.5$ ,  $z = .709$ ,  $p = .535$ . The same was found for hypothesis 11 with  $H_0$ : *The mean ranks of communication with GP scores for the two mammography groups are equal.* Both groups have the same experience with healthcare,  $U = 81$ ,  $z = -.832$   $p = .453$ , and, thus, both null hypotheses must be accepted.



Table 16

*Mann-Whitney U test on mammography groups and both communication with GP and experience with healthcare*

	Communication with GP	Experience with healthcare
	<i>mdn</i>	
Yes	1	2
No	1	2
Total	1	2

Hypothesis 12, with H0: *The distribution of both health literacies scores for the two mammography groups are equal*, showed that the distributions of the SILS 1 score for those who had not (mean rank = 16.23) was higher than the ones who had (mean rank = 15.44) (see appendix 3 - boxplots). However, the difference was not statistically significant,  $U = 104$ ,  $z = .234$ ,  $p = .848$ . While the distribution for SLIS 2 shows a reversed difference (see appendix 3 - boxplots), where those who did not have a mammography (mean rank = 16.44) had a higher literacy score than the ones who had (mean rank = 18.50), this difference is also statistically insignificant,  $U = 94.5$ ,  $z = -.566$ ,  $p = .592$ . Thus, it in this sample there is no difference in the two SILS scores and the two mammography groups.

### **Content Analysis**

A quantitative content analysis was used for the three open questions: experience with Dutch healthcare, perception on Dutch healthcare, and recommendation for increasing participation of high-risk non-Dutch mother tongue speaking women in breast cancer screening. Each answer is given one or more codes in which the pattern is inductively observed.

#### **Experience with Dutch Healthcare**

The participants were asked what their own experience are with Dutch healthcare. In total, 22 participants gave their answers. The answers showed both 11 times a positive experience and 11 times a negative experience. The positive answers were divided into three codes: Positive experience due to 'being understood by the doctor' ( $n = 1$ ), 'having no language barriers' ( $n = 3$ ), and 'having accessible healthcare' ( $n = 7$ ). The negative answers were divided into four codes: Negative experience due to 'a lack of medical knowledge of the doctor' ( $n = 2$ ), 'healthcare not being accessible' ( $n = 2$ ), 'not getting needed medical treatment' ( $n = 3$ ), and 'not being understood by the doctor' ( $n = 4$ ) (see table 17).

Table 17

*Codes experience with Dutch healthcare*

Codes	N	Example
<i>Positive experience</i>		
Being understood by the doctor	1	'My doctor is very involved and helpful enough'
Having no language barriers	3	'It was possible for me to communicate with them in English'
Having accessible healthcare	7	'I have always had help when I need it.'
<i>Negative experience</i>		
A lack of medical knowledge of the doctor	2	'Every time that I have to attend, I have to indicate to the GP which medical exams and medications to take. Extremely disappointing.'
Healthcare not being accessible	2	'I have to really push to be able to receive help.'
Not getting needed medical treatment	3	'For example, I suffered from kidney inflammation a month ago, while the GP thought I had cystitis and gave me medicines for this.'
Not being understood by the doctor	4	'I never felt like my health problems or concerns were taken seriously.'

**Perception Towards Dutch Healthcare**

While the previous question was on their experience with participating in healthcare, this open question was for the participants who had a perceived barrier in getting good healthcare in the Netherlands. In total 15 participants answered which were settled in the following five categories: perceived barriers due to 'language barriers' (n=1), due to 'a lack of preventive care' (n = 2), due to 'problems with insurance' (n = 2), due to 'a lack of empathy/understanding' (n = 7), and due to 'a lack of specialist care' (n = 8) (see table 18).

Table 18.

*Codes perception towards Dutch healthcare*

Codes	N	Example
Language barrier	1	"(...), language barriers, only life (...)"
Preventive care	2	'The Netherlands healthcare system doesn't care about preventive care'
Insurance	2	'I'm paying private insurance, and no one will gamble with my health'
Empathy/Understanding	7	'I feel ignored and doctors make me feel like I'm exaggerating that I want to check on my health from time to time'
Specialist care	8	'Difficulties with regular check-ups, seeing specialists'

### Recommendation for Increasing Participation

The participants were asked how in their own opinion, high-risk non-Dutch mother tongue speaking women could be motivated to participate in breast cancer screening. In total, 34 participants gave their answers. The answers were categorised into six codes: participation of High-Risk non-Dutch mother tongue speaking women in breast cancer screening can be improved by 'increasing cultural sensitivity' (n = 2), by 'using the GP for access' (n = 2), by 'increasing their health literacy' (n = 3), by more (online) visibility (n = 6), by having 'more accessible information' (n = 11), and by providing 'more translations' (n = 20) (see table 19).

Table 19

*Codes recommendation to increase participation of High-Risk group in breast cancer screening*

Codes	<i>N</i>	Example
Increase cultural sensitivity	2	'Explore other cultural boundaries that possible patients might meet.'
Use GP for accessibility	2	'Their GP should send them for investigation regularly (once a year or so).'
Increase health literacy	3	'through making sure they understand first how the medical system works here as it is different from many home countries'
More (online) visibility	6	'The first thing that comes to my mind are the Facebook groups for migrants/foreigners in Netherlands, since the Dutch healthcare seems to be an occurring topic there.'
More accessible information	11	'By being more involved in the communities and communicating them better about their options'
More translations	20	'By facilitating the message into different language and always having a translator'

## Discussion

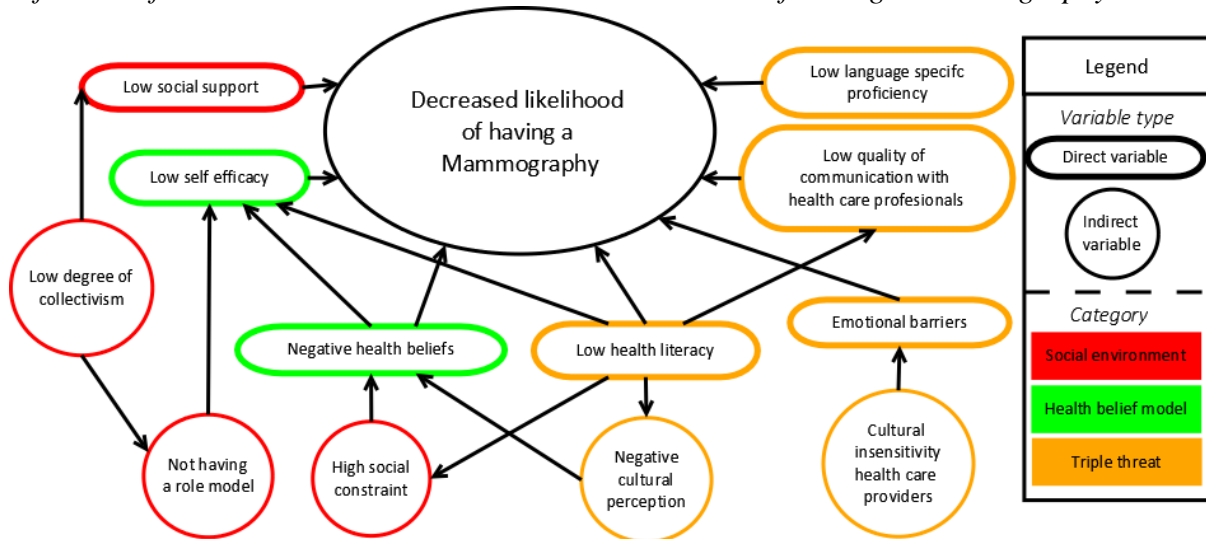
Based on the presented theories and previous empirical evidence, the discussion section will explain the results, the suitability of the used methods, as well as the recommendations based on this study's findings for both future research and for the community.

### Discussion High-Risk Group

As mentioned in the methods, because of the small number of participants from the high-risk group ( $n = 2$ ) it was impossible to analyse the effects of cultural factors on their accessibility to breast cancer screenings. Thus, the first sub-research question, which refers to women in the high-risk group, could not be answered by the collected data. However, based on previous research this study was able to provide a conceptual diagram showing the direct and indirect variables that decrease their likelihood of having a mammography (see conceptual diagram 1).

Possibly, the lack of respondents from the high-risk group was due to the chosen instrument: a digital self-administered questionnaire. Although, it provides a wider outreach than traditional questionnaires, it has been found to cause a lower response rate (see Bryman, 2016). Besides, individuals with low digital literacy skills were at a disadvantage, as they do not have the capabilities to self-administer and complete a digital questionnaire successfully. These concerns were already known before the questionnaire was distributed, which is why in its introduction the respondents were asked to assist others with lower digital literacy skills (see appendix 1 – introduction). However, as the unpredicted COVID-19 pandemic happened, it is likely that participants were unable to do this.

## Conceptual Diagram 1

*Influence of indirect and direct variables on the likelihood of having a mammography*

The conceptual diagram above visualizes how different direct and indirect variables influence the likelihood of having a mammography (see appendix 4 for the sources of these relations). The variables were grouped into three categories: social environment, health belief model, and triple threat. The direct variables contained in the triple threat group are language-specific proficiency, quality of communication with healthcare professionals, emotional barriers, and low health literacy. Furthermore, in the health belief model category two direct variables were identified, self-efficacy and health beliefs. The latter includes the four original HBM domains. Moreover, the social environment listed only one direct variable, social support. On the other hand, indirect variables were only found in the social environment and triple threat category, which, interestingly, influence the direct variables of the health belief model. Particular attention should be given to the health literacy variable, which is dominant in the diagram as it influences both the health belief model and social environment variables.

Thus, when applying the diagram to the high-risk non-Dutch mother tongue speaking women, it becomes visible that the best way to increase the accessibility of breast cancer screening is by making changes in the social environment, among healthcare professionals, and with the women themselves. First, the social environment should increase their collectivism (or altruistic behaviour), limit their social constraints, increase their social support, and provide a role model to these women. Secondly, the healthcare professionals need to adjust their practices to the different perceptions on healthcare, language proficiency, and health literacy skills of this group. For this, extra attention should be given on the communication between patient and healthcare professionals. Lastly, the diagram shows that increasing these women's

language proficiency in the national language as well as their health literacy can, directly and indirectly, contribute to a higher likelihood of having a mammography. Ultimately all three components have the potential to increase early detection and lowered breast cancer's mortality rate.

### **Discussion Social Environment**

The data collected was suitable to partially answer the sub-research question related to the social environment, where the analysis of the closed and open-ended questions provided insights into the cultural factors. These findings are especially relevant because the individuals in this group, the non-Dutch mother tongue speaking women below the age of 50, are going to be the high-risk women of the future.

#### **Significant Findings**

The statistical tests on the closed questions found two significant relations between high language proficiency and the two dependent variables of negative perspective on accessibility of good healthcare and positive experience with healthcare. The combination of these two relations *together* have not been found before in previous research (cf. Jacobs et al., 2005; cf. Woudstra et al., 2016; cf. Sarma, 2015; cf. O'Hara et al., 2018). However, a viable explanation for this can be found in *the integration paradox*, which states that individuals with a migration background who are higher educated and have a higher language proficiency are more disengaged with their current country of residence (Buijs, Demant & Hamdy, 2006). This creates the paradoxical effect of decreasing an individual's wish to return to their country of origin while increasing their experiences of discrimination (Di saint Pierre, Martinovic & de Vroome, 2015). The latter is the result of an elevated level of *relative deprivation*, which is caused by both having an higher expectation regarding equal opportunity and treatment (de Vroome, Martinovic & Verkuyten, 2014; Smith et al., 2012) as well as having an increase in cognitive capabilities to critically reflect on unfair processes (Wodtke, 2012).

When applying the paradox to this study's findings, the following can be assumed: High language proficient individuals do not *experience* objectively more barriers, as shown by their higher proportion of positive experience with healthcare. However, the high language proficiency does give them the cognitive ability to better *perceive* unfair processes and discrimination in accessing good healthcare, which leads to a feeling of relative deprivation. This discovering is pioneering a new perspective on language proficiency and health

behaviours, where previous notions which only considered that increase in proficiency to provide positive effects is challenged. Thus, in a nutshell, this study found that an increase language proficiency in the national language can contribute to increased barriers to participating in breast cancer screening.

### **Insignificant Findings**

As stated before, the descriptive statistics already showed that there was no difference between the wide variety of variables and the groups' religion and migration background. Also, the inferential tests showed insignificant differences between most of the variables, which will be mentioned shortly.

All the language proficiency groups showed similar health literacies scores, which is in line with previous research, as language proficiency and health literacy are both variables that influence health behaviours, but they are not predictors of each other (see Woudstra et al., 2016; see Berkman et al., 2011). This means that it cannot be assumed that individuals with low health literacy also have low language proficiency. However, the fact that there was no difference between mammography groups and health literacies scores is contradictory to previous findings (see Baars et al., 2017; see Berkman et al., 2011), which might be due to the domains of health literacy measured in the SILS. This scale has been criticised for its narrow approach (see Jordan, Osborne & Buchbinder, 2011) as it mainly measures comprehensive reading abilities, which can be an explanation of why the highly educated participants in this study did not measure differently based on their mammography experience.

The study also found that in the language proficiency and the mammography groups there was no difference in whether participants communicated with their family members about breast cancer. A possible explanation for this could be the degree of collectivism, which increases the strength of social constrain, as most of the participants identified as having Turkish and Latin American heritage, which are regions that have higher degrees of collectivism than west-European societies (Minkov & Hofstede, 2010). This possible stronger social constraint can make taboos on breast cancer more prominent. However, to assess the validity of this explanation, further research is needed.

All the other insignificant differences found in this study also contradict previous research. For example, similar health knowledge between the low and high language proficiency individuals was identified (cf. Woudstra et al., 2016), and the same rating of communication with the GP between mammography and language proficiency groups (cf. Baars et al., 2017; cf. Davis et

al., 2002; cf. Diviani et al., 2015; cf. Woudstra et al., 2016). A possible explanation might be the high education level of the sample. Nearly all participants have 13+ years of education, which can act as a buffer for the influence of low language proficiency on factors such as communication with GP, health knowledge, and even on the health behaviour of participating in breast cancer screening. However, this assumption cannot be confirmed with the collected data, thus further investigations are needed.

### **Content Analysis**

The closed questions provided new insights into the visible and significant difference of the various variables. However, they do not provide the individuals' argumentations. To enhance this study's understanding of factors that contribute to barriers in breast cancer screening a quantitative content analysis was conducted of the answers on three open-ended questions.

The content analysis found that individuals had a negative perception on the accessibility of good healthcare due to lack of empathy/understanding from healthcare professionals as well as perceived barriers in getting specialist care. These findings are in line with previous studies where emotional barriers and a low quality of communication with the healthcare professionals cause negative perceptions (see Baars et al., 2017; see Kristiansen et al., 2016; see Woudstra et al., 2016).

In addition, participants said to have positive experience with healthcare when there were no language barriers or limitations in accessing healthcare. However, they had a negative experience when they were not being understood by healthcare professionals and if they did not get the needed treatment. Thus, it became visible that once again both communication with the healthcare professionals and language proficiency played a role in dictating their experience with healthcare (see Jacobs et al., 2005; see Woudstra et al., 2016). Based on the analysis of the answers it can be assumed that to increase positive experiences with healthcare, the focus should be on improving communication between patient and healthcare professionals as well as limiting the barrier of language proficiency.

The last content analysis was on the participants' recommendations on how participation in breast cancer screening can be increased. According to them, successful changes to current practices would be the increase and accessibility of information and its translation, as well as creating more (online) awareness tailored to the different linguistic and literacy abilities of women.



## **Limitations**

The present study has four predominant limitations: the usability of the results, the sampling methods, the use of self-administered questionnaires, and the external circumstances.

First of all, it is vital to understand that this pilot study was not meant, or is suitable, for the essentialist approach to cultural barriers in breast cancer screening. Due to its small sample, the study was consciously limited not to have a generalising ability on specific groups with similar cultural heritage or on the whole target population. As a big, highly representative, sample is needed if one wants to analyse how societal processes systematically treat specific groups differently.

A crucial limitation in this study was the use of snowball sampling as well as the use of LinkedIn for the first release of the questionnaire. The snowball sampling was not suitable as it is highly likely that sensitivity of the research topic resulted in a lack of willingness to participate and to share the questionnaire with others (see Parhizkar, Nazari & Hassan, 2012). The same explanation might also be the reason why specific questions in the questionnaire have a high amount of missing answers, such as participants' own and their family's experience with breast cancer. In addition, the use of LinkedIn, a social media platform for professionals who want to extend their work-related network, caused for nearly only high educated non-high-risk individuals.

Another limitation was the use of a self-administered questionnaire. This tool usually provides an easy way to reach a broad audience quicker and cheaper than physical or oral questionnaires, it limits the interviewers' effect, and allows the participant to answer the questions in their own time and at their preferred setting which could have been an advantage due to the possible sensitivity surrounding the topic (see Bryman, 2016). However, using a digital question let to the possible exclusion of individuals with low digital literacy skills.

The final limitation is the time in which the study was conducted. As stated before, the period of the research was during the COVID-19 pandemic. While the possible effects on mental health is not known yet, it can be assumed that the intelligent lockdown of all non-essential work and forcefully suggestion by the government to stay at home, caused an increase in emotional distress among participants as well as willingness and availability to participate in the research. The impact the pandemic had on the results can only be known if this exact study would be redone in the future after the pandemic is over.

## **Recommendations**

This study has a pilot nature, meaning that its purpose is to test the feasibility of the chosen tools, methods, and approaches with the intention to assess the role of cultural factors on breast cancer screening participation and to, ultimately, results in a larger-scale research.

### **Future Research**

The findings offer evidence that using a self-administered questionnaire as well as distributing through a snowball sampling and LinkedIn is not suitable for high-risk non-Dutch mother tongue speaking individuals. Thus, future research should use other tools and distribution methods, for example, going to a community centre with paper questionnaires. Secondly, the focus of the questionnaire should be on investigating the role of language proficiency, health literacy and education level on barriers in breast cancer screening.

Based on the results, there is a need for early-on interventions for the non-high-risk group (below 50 years), with a specific emphasis on perception towards healthcare as well as on patient-focused and intercultural communication of healthcare professionals. Because especially women who have high language proficiency and are highly educated might be less susceptible to participate in recommended health behaviours. In addition, non-high-risk women need to be aware of their impact on the social support for current high-risk individuals, where they can play an active role in motivating the participation in breast cancer screening.

### **For the Community**

For organisations involved with the community, the following three recommendations can be taken from this study.

First, to limit the influence of social constraints and increase social support, it is essential to understand the role of collectivist culture in health behaviours. A direct change that can be implemented is the creation of role models for high-risk women who openly communicate about breast cancer and the importance of breast cancer screening. Secondly, digital and physical communications about breast cancer screenings should not be solely based on cultural heritage but adjusted to each woman's language proficiency, health literacy, and educational level. Here communication approaches such as patient-focused and intercultural can be used to assess the different factors that create barriers instead of a generalising assumption based on one's cultural heritage. Finally, to create a sustainable increase in breast cancer screening's participation, but also to improve the likelihood of adopting other health

behaviours among women who do not have Dutch as their mother tongue, the focus should be on improving their Dutch language proficiency and health literacy.

### **Reflection with the Community**

The different recommendations as well as the limitations and results of this study was discussed with the community collaborator, the Mammarosa Foundation. To facilitate the conversation a clear overview was created in Dutch containing all the vital components of the study (see appendix 5).

During our talk, they recognized based on their own experience how the integration paradox can cause barriers in accessing breast cancer screening. In addition, a new research question aroused, primarily on what the results would be among individuals who do have Dutch as their mother tongue. This is something worth exploring in future research.

Based on the created recommendation for the community, the Mammarosa Foundation expressed their interest in the implementation of role models. According to them, the formation of role models is a feasible addition to their current practice, in where they will play an active role in the communication and awareness creation of breast cancer within the different communities. Furthermore, the Foundation expressed their interest in concentrating on creating accessible information adapted to different literacy skills and language proficiencies.

## Conclusion

The presented community-based pilot study used a multidisciplinary and critical approach towards soft-essentialism culture ideology to answer the research question '*How are health literacy, cultural perception, and past experiences of non-Dutch mother tongue speaking high-risk women and their social environment related to accessing breast cancer screening*', for which a quantitative approach was used with a self-administered questionnaire containing open-ended and closed-ended questions.

Unfortunately, the sample was not suitable to provide insights into the high-risk non-Dutch mother tongue speaking women. However, the study was able to provide a visual overview of how different cultural factors influence the likelihood of participating in breast cancer screening. The sample size of the social environment group, which were all non-high-risk non-Dutch mother tongue speaking women, was sufficient to provide a bird-eye overview. However, a limitation was that almost all the individuals in this group were highly educated.

The results showed that having a high language proficiency can result in a negative perspective on the accessibility of good healthcare and positive experience with Dutch healthcare, which might be due to the so-called integration paradox. Other tests on the communication with family, with their GP, as well as knowledge about breast cancer were found insignificant, which might be due to the high education level of the participants.

This quantitative pilot study concludes that it is crucial to focus on increasing these women's language proficiency and health literacy, and in the future research a different tool and distribution method should be used. The next step in forthcoming investigations needs to be the creation of early-on interventions for non-high-risk individuals focused on increasing open-communication, social support, and positive perspectives towards Dutch healthcare. Due to the reality that these women are the current social environment as well as the future high-risk group.

Overall, the recommendation is to create role models, accessible information on breast cancer, as well as patient-focused and intercultural communication techniques for healthcare professionals. All of them, should be adjusted to women's language proficiencies, health literacies, and educational level. Finally, to improve the general adoption of new health behaviour, the focus should be on improving their Dutch language proficiency and health literacy skills.

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