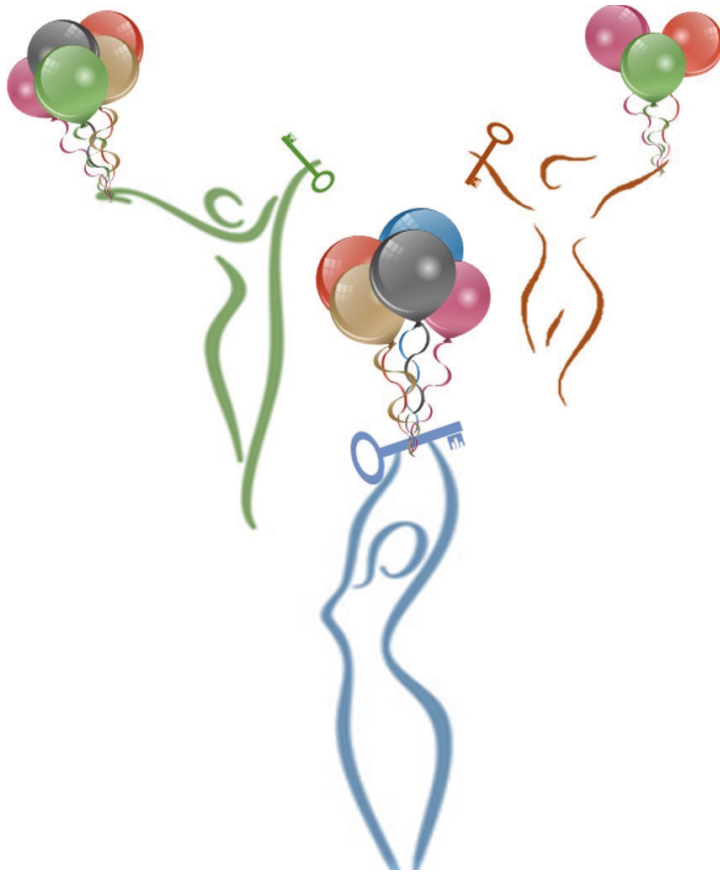


Access to and participation in mammographic screening within a region in Sweden

Maria Norfjord van Zyl



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No. 323

ACCESS TO AND PARTICIPATION IN MAMMOGRAPHIC SCREENING WITHIN A REGION IN SWEDEN

Maria Norfjord van Zyl

2020



School of Health, Care and Social Welfare

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Maria Norfjord van Zyl

Akademisk avhandling

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för hälsa, vård och välfärd kommer att offentligen försvaras fredagen den 18
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Fakultetsopponent: Professor Christine Kumlien, Malmö Universitet



Akademin för hälsa, vård och välfärd

Abstract

The population-based mammographic screening programme offers every woman in Sweden between 40 and 74 years of age a mammogram with the purpose of early detection of potential breast cancer. The programme is seemingly equal in its setup; however, approximately 20 percent of the women do not participate in the screening. The overall aim of Sweden's public health policy is to create prerequisites for good and equal health, and health care, a health determinant, falls under the responsibility of the self-governed Regions. Therefore, it is important to analyse regional participation in mammographic screening to develop strategies to reach those who refrain from screening.

The aim of the doctoral dissertation was to describe, explore and understand access to and participation in health care using mammographic screening as an example. Study I was a quantitative cross-sectional study based on individual and aggregated data. The analysis consisted of frequencies of data, multivariate logistic regressions, and pairwise chi-square tests. Study II used group discussions with women participating in mammographic screening for data collection. In Study III, women who had not participated in mammographic screening for at least the last two invitational rounds were interviewed. In Study IV, interviews with regional politicians were conducted. The method of analysis for Studies II and III was qualitative content analysis, and in Study IV a reflexive thematic analysis was performed.

The results show that access to and participation in mammographic screening involve both structural and individual conditions. Municipality of residency as a potential proxy for distance to the mammographic facility is indicated to impact participation, as is age. Getting to and from the facility and taking time off from work are examples of structural conditions. Facilitators for and barriers to participation in mammographic screening are similar for women who participate and women who lately have not. The phases of the screening process are addressed. Psychological preparation before the visit, encounters with the staff, and managing the wait for the results reflect individual determinants. Caring for health is perceived as a shared commitment between politicians and individuals. This responsibility requires information and understanding of the impact social determinants have on the decision to participate in the screening. It also requires resources for the lowering of thresholds for participation.

Encounters with the health care system and the health care systems responsiveness are important for continuous participation in mammographic screening, whereas information and knowledge are pivotal to making well-informed decisions.

*To my parents Siw and Lennart
and
to my husband and life partner Awen*

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Encounters with the health care system and the health care systems responsiveness are important for continuous participation in mammographic screening, whereas information and knowledge are pivotal to making well-informed decisions.

Key words: Access, experiences, mammographic screening, participation, perceptions, public health, qualitative content analysis

Populärvetenskaplig svensk sammanfattning

Mammografi erbjuds alla kvinnor, i åldersgruppen 40 till 74 år, som är folkbokförda i Sverige för att upptäcka potentiell bröstcancer. Erbjudandet kan anses jämlikt, men cirka 20 procent deltar inte screeningen. Om det beror på påverkbara faktorer, utom kvinnornas direkta kontroll, så kan det vara ett uttryck för ojämlikhet. Att skapa förutsättningar för en god och jämlik hälsa i hela befolkningen är det övergripande målet i Sveriges folkhälsopolitik, och hälso- och sjukvården kan anses vara en viktig bestämningsfaktor för hälsan. Då de självstyrande Regionerna ansvarar för hälso- och sjukvården är det av vikt att Regionerna analyserar delaktighet i mammografisk screening för att kunna utveckla strategier för att nå grupper som uteblir från screeningen. Det övergripande syftet med doktorsavhandlingen var att beskriva, undersöka och förstå tillgänglighet och delaktighet i hälso- och sjukvård, genom att använda mammografisk screening som ett exempel, utifrån ett svenskt regionalt perspektiv.

Doktorandprojektet omfattade fyra studier. Studie I använde kvantitativa data för att statistiskt beskriva och analysera icke-deltagande i mammografisk screening i relation till kommundeltagande och ålder. I Studie II genomfördes gruppdiskussioner med kvinnor som deltog i mammografisk screening. Individuella intervjuer genomfördes i Studie III med kvinnor som inte deltagit i screeningen de två senaste tillfällena de erbjudits screening, och i Studie IV intervjuades regionala politiker. Analys av kvalitativa data utfördes utifrån principer för innehållsanalys samt tematisk reflexiv analys.

Resultatet visar att tillgänglighet och delaktighet i mammografisk screening innefattar både individuella och strukturella förutsättningar. Många faktorer påverkar tillgänglighet och delaktighet i mammografisk screening, från samhälls- och politisk nivå till individens livsvillkor. Den kommun där kvinnorna bor och var kommunen är belägen i förhållande till var den mammografiska enheten är belägen, kan inverka på delaktighet, likaså att tillhöra åldersgruppen 40 – 44 år, i jämförelse med äldre åldersgrupper. Alla de olika faserna screeningprocessen innefattar berörs. Det kan till exempel vara kvinnornas beslutsfattande innan undersökningen och kommunikationsmöjligheter till och från mammografienheten. Ansvar för hälsa och åtgärder för att värna den ligger både hos de regionala politikerna och individen. Ansvar förutsätter information och förståelse för de sociala bestämningsfaktorer som inverkar på beslutet att delta eller inte i mammografisk screening och resurser krävs för att sänka trösklar för att underlätta delaktighet i screening

Hälso- och sjukvårdens lyhördhet för kvinnornas behov är viktig för fortsatt delaktighet i mammografisk screening, varav information och kunskap är avgörande för att fatta välinformerade beslut. Det gäller såväl för de som blir erbjudna mammografisk screening som de politiska beslutsfattarna.

Nyckelord: Delaktighet, erfarenheter, folkhälsa, kvalitativ innehållsanalys, mammografisk screening, tillgänglighet, uppfattningar

List of Papers

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

- I. Zidar, M. N., Larm, P., Tillgren, P., & Akhavan, S. (2015). Non-attendance of mammographic screening: The roles of age and municipality in a population-based Swedish sample. *International Journal for Equity in Health*, 14(157), 1–11.
<https://doi.org/10.1186/s12939-015-0291-7>
- II. Norfjord van Zyl, M., Akhavan, S., Tillgren, P., & Asp, M. (2018). Experiences and perceptions about undergoing mammographic screening. A qualitative study involving women from a county in Sweden. *International Journal of Qualitative Studies on Health and Well-Being*, 13(1521256), 1–10.
<https://doi.org/10.1080/17482631.2018.1521256>
- III. Norfjord van Zyl, M., Akhavan, S., Tillgren, P., & Asp, M. (2020). Non-participation in mammographic screening – Experiences of women from a region in Sweden. *BMC Public Health* 20(219), 1–11.
<https://doi.org/10.1186/s12889-020-8306-8>
- IV. Norfjord van Zyl, M., Tillgren, P., & Asp, M. (2020). The politician's perspective on mammographic screening – An interview-based study from a region in Sweden. *Submitted to BMC Health Services Research*.

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Preface

Having a nursing background, I sometimes felt that some factors were missing in the attempts to explain and understand why some patients did not comply with the advice given to maintain their reclaimed health, or the accumulation of several less healthy habits among certain groups of people. Of course, I understood that the reasons are more complex than, for example, merely pathophysiology, health beliefs and one's own choices.

When making the decision to change career, I felt attracted to studying the public health sciences due to their complementary nature to the nursing science. The study of the public health sciences introduced me to the elusive connection of jigsaw pieces that address the question of potential reasons for non-compliance, namely the social determinants of health. These determinants offer explanations regarding the complexity of health and the many different factors embedded within the different determinants of health, such as access to health care, as well as psycho-social aspects such as being a participant rather than an attendant in a health service or treatment. Further, the understanding of social determinants opened a door to equity in health or the lack thereof, accompanied by an understanding that differences in resources may result in inequity in health. This led me to the next phase in my life: embarking on the trials and tribulations of a doctoral student. A research project focused on a seemingly equally offered health service, namely mammographic screening, became a 'tool' to investigate the overall question why approximately 20 percent of invited women decline the offer to undergo the screening. What are the determining factors that may facilitate the decision to partake in mammographic screening, and are there some factors that can be adjusted within reason? This highlighted an important issue, as this question can be approached from many different angles. With this said, I have tried to keep true to the public health sciences and do them justice.

Introduction

This doctoral dissertation derives from an interest in investigating and understanding access to and participation in mammographic screening. Mammographic screening is seemingly equal in its set-up, as it is offered to every woman between 40 and 74 years of age residing in Sweden who has a postal address. To participate is a free choice; however, should the reason to decline mammographic screening be determined by adjustable factors beyond the individual's direct control, it can be argued that this decision had already been made by the state and self-governed regions (previously known as county councils), which are responsible for structural conditions, on behalf of the individual. This does not fully meet the Swedish Health and Medical Care Act (SFS [Swedish Statute Book] 2017:30) that stipulates respect for humans' equal rights as well as autonomy.

By investigating the reasons behind the decision to participate in or refrain from mammographic screening, potential patterns and common denominators can be identified. By doing so, differences that might indicate inequity can be addressed, which is of importance for the individual, the public health of a country and the state.

Background

The health care system and mammographic screening

In Sweden, the health care system, as a part of the welfare system (Blomqvist, 2004), is partially decentralized, as it is in, for instance, Belgium, Croatia, Denmark and Finland (Soldi & Odone, 2017). This means that health care falls under the responsibility of the national government, which has delegated the operational side of health care to the 21 regions and the 290 municipalities (Mossialos, Djordjevic, Osborn, & Sarnak, 2018). The regions are governed by directly elected representatives (Anell, Glenngard, & Merkur, 2012) in charge of the delivery of health services, health care planning and organization (Soldi & Odone, 2017). The financing of health care is essentially done through regional taxes, with some contribution from the government (OECD [Organisation for Economic Co-operation and Development], 2019). The highest authority within a region is the Regional Assembly, which makes decisions about the region's budget, organization and management, with the power to delegate some responsibilities to other committees within the region. The Assembly also appoints the Regional Executive Committee, which are empowered to lead and coordinate the decisions made by the Regional Assembly, as well as overseeing the finances (Swedish Association of Local Authorities and Regions [Sveriges Kommuner och Regioner], 2020). The Regional Executive Committee can also appoint other committees and subcommittees which are delegated certain responsibilities; examples of such subcommittees are the Subcommittee for Public Health and Health Care and the subcommittee for regional development (Region Västmanland, n.d). Due to the fairly high level of self-governance of health care in the regions, both access and quality may differ between regions within the country (Soldi & Odone, 2017).

The health care system covers different levels of disease prevention, where screening falls under the term 'secondary prevention' and aims at early detection of potential illness/disease (World Health Organization Regional Office of Europe, 2014), and screening for cancer can be regarded as part of cancer care (Chiu, 2003).

Mammographic screening

Of all cancer diagnoses for females globally, in 2018, breast cancer accounted for 24.2 percent, equivalent to 2,088,849 cases. Besides being the most commonly diagnosed cancer among females, breast cancer is also the primary cause of deaths in cancer (Bray et al., 2018). In 2018 for Sweden, breast cancer represented 28.4 percent of all new cancer cases for females, translating to 8,017 cases (Ferlay et al., 2018).

This statistic clearly shows the impact breast cancer has on the burden of disease, public health and the individual, and this understanding is unfortunately not new, even though the statistics have changed over time. As early as 1964, Robert L. Egan, Doctor of Medicine, declared breast cancer to be a severe public health problem and that mammography was a promising screening method for the early detection of potential cancer in women showing no symptoms of any abnormalities in the breasts; however, evaluation needed to be carried out over time to assess its efficacy (Egan, 1964). The value of a mammogram (an x-ray examination) is that the early detection of potential cancer facilitates the commencement of early treatment (Lee & Elmore, 2014).

The benefits and negative consequences of mammographic screening have been vividly discussed over the years. Some benefits are reductions in mortality, such as a decrease of 24.0 percent according to a Swedish report (Swedish Cancer Society, 2004), whereas an independent panel on breast cancer assessed a 20 percent risk reduction of breast cancer mortality (Independent UK Panel on Breast Cancer Screening, 2012). A consensus regarding the benefits of mortality reduction from mammographic screening has, however, not been reached, as it also has been found that the impact of the screening may be very modest (Autier, Boniol, Gavin, & Vatten, 2011; Bleyer, Baines, & Miller, 2016). Negative consequences that have been articulated concern, for instance, occurrences of breast cancer at the mammographic screening that would not otherwise have been found clinically in the woman's lifetime (Puliti et al., 2012). The over-diagnosing of breast cancer, the recalling of women for further examination due to false-positive test results, and exposure to radiation are examples of harms with mammographic screening (Houssami, 2017; Lauby-Secretan et al., 2015). Both the benefits and harms are important to inform the invited women about so they can make a well-informed decision about whether to participate (Hersch, Jansen, & McCaffery, 2018; Sagan, McDaid, Rajan, Farrington, & McKee, 2020). The controversy of benefit versus harm with mammographic screening, as well as the information provided to the invited women about this issue, has been discussed (Independent UK Panel on Breast Cancer Screening, 2012; The Lancet, 2009) in different countries and media. In addition, the confusion and controversy that the contradicting messages may create for the women being invited to screening have also been addressed (Kumlien, 2018).

Mammographic screening programmes are a public health strategy that requires coordination, financing, infrastructure, a health care organization that can treat those diagnosed with tumours and evaluation systems for assessing the programmes' efficacy and quality (World Health Organization, 2014). This evaluation should include identifying potential obstacles such as health system structures, uptake and the users' experience of the screening to assure a positive encounter, which in turn may influence other users (women) to participate in screening (Sagan et al., 2020).

Population-based mammographic screening is offered in 25 of the 28 member countries of the European Union (Ponti et al., 2017). In Sweden, the mammographic screening programme was fully implemented in 1997 (Olsson et al., 2000) and today is offered to all women between 40 and 74 years of age, every second year. The woman must be nationally registered in Sweden, with a registered address to which the invitational letter from the mammographic facility can be sent. The invitation consists of some information about the examination and a pre-booked examination time. The time and date can be re-scheduled if it is not suitable. For a national screening programme to be cost-effective requires a high participation rate (Törnberg, Lidbrink, & Henriksson, 2014), with at least 70 percent of the risk group participating and an organization that caters to all aspects of effective and efficient health service (World Health Organization, 2007). However, this can pose a challenge over a longer period of time (OECD, 2013), and in order to increase the participation rate, mammographic screening became free of charge in every region in Sweden from July 1, 2016. This was also an initiative to increase the participation rate for women from more socio-economically challenged groups and consequently strive for more equitable health care (Government Bill 2015/16:138).

Previous research regarding access to and participation in mammographic screening

As previously mentioned, screening is one strategy that aims to serve the public health, since it may lead to early detection and early treatment and is cost-effective (Feig, 2006). However, some women decline the offer to participate in the mammographic screening. Age has been seen as linked to participation, as the tendency to not participate in the screening has been found among older-aged women (Flytkjær Jensen, Pedersen, Andersen, & Vedsted, 2012; Petrelli et al., 2018). The opposite situation for participation has also been found in a study for women above 64 years in comparison to women aged between 50 to 64 (Larsen, Moshina, Sagstad, & Hofvind, 2020). Socio-economic factors, which include the triad of education, occupation and income (Adler & Newman, 2002), are associated with non-participation in mammographic screening. Regarding educational level, a lower level of education (Damiani et al.,

2012), as well as a higher level, have both been related to non-participation (Zackrisson, Andersson, Manjer, & Janzon, 2004). A higher educational level has, however, also been found as linked to participation in mammography (Kriaucioniene & Petkeviciene, 2019). Unemployment and low income are also related to non-participation (Edgar, Glackin, Hughes, Mary, & Rogers, 2013; Flytkjær Jensen et al., 2012; Zackrisson et al., 2004). Another factor that is linked to refraining from mammographic screening is origination from a country other than the country of residency (Jack, Møller, Robson, & Davies, 2014; Flytkjær Jensen et al., 2012; Lagerlund et al., 2002; Renshaw, Jack, Dixon, Møller, & Davies, 2010). Distance to screening (Jensen, Pedersen, Andersen, Fenger-Gron, & Vedsted, 2014), which may require access to a car in order to get to the mammographic facility; travel time and season (Onitilo et al., 2014); and living in a geographic location that does not provide the screening service in proximity to where one resides (Guillaume et al., 2017; Leung, McKenzie, Martin, & McLaughlin, 2014; Nogueira et al., 2019; Simou, Fountoulakis, Kourlaba, & Maniadakis, 2011) also have a negative impact on accepting the invitation to have a mammogram. Residing in a city, in comparison to a village or a town, increased the odds of participation in mammographic screening (Kriaucioniene & Petkeviciene, 2019). The influence of neighbourhood of residence itself within a city, in relation to not participating in mammographic screening, has also been investigated, indicating not to influence non-participation (Lagerlund, Merlo, Vicente, & Zackrisson, 2015). Another study focused on participation in mammographic screening from an ethnicity perspective, identified by data of postal code within a metropolis, which offered an understanding of the likelihood of the woman belonging to a certain ethnic group. The result indicated a higher likelihood of refraining from a mammogram if living in an area with a large population of Black residents (Renshaw et al., 2010).

More personal reasons for not participating in mammographic screening involve psycho-social factors such as a low level of social support, which is defined in part as contact with friends and family, someone to talk to when in need and the availability of practical help (Documet et al., 2015; Flytkjær Jensen, Fischer Pedersen, Andersen, & Vedsted, 2015). Other examples of reasons to refrain from the mammogram are fear of pain or of receiving a negative test result (Manjer, Zackrisson, & Emilsson, 2016; Marmara, Marmara, & Hubbard, 2018; Saadi, Bond, & Percac-Lima, 2012; Watson-Johnson et al., 2011) and insecurity about how well the examination can actually detect potential cancer (Watson-Johnson et al., 2011). The fear of getting breast cancer can also be a motivator to participate in mammographic screening (Drossaert, Boer, & Seydel, 2005). The personal encounter between the woman and the personnel at the mammographic facility is important as well, as insensitive, inattentive and disrespectful treatment may result in non-participation in mammographic screening (Johansson & Berterö, 2003; Lagerlund, Widmark,

Lambe, & Tishelman, 2001; Manjer et al., 2016). All findings from the studies above link non-participation to a variety of social determinants of health.

The research in relation to health and welfare

In public health sciences, which embraces many disciplines, health and welfare are areas of interest (Tulchinsky & Varavikova, 2014). Both health and welfare are resources in everyday life and can interact with each other in different ways depending on how the concepts are defined and in what context these concepts are used.

Health is a human right (United Nations Committee on Economic & Rights, 2000; United Nations [UN], 1948; World Health Organization, 1948), irrespective of socio-economic background, religious and political beliefs and race (World Health Organization Regional Office of Europe, 2013). In addition, health is valuable for the individual as well as for the nation, since a healthy population contributes to economic growth and well-being (Brown, Harrison, Burns, & Ziglio, 2013), and healthy individuals are more able to benefit from education, consequently increasing the chances for employment and sustenance (SOU [Swedish Government Inquiries] 2017:47). In a person's life, certain support in regard to an individual's and a population's health situation can be needed. Health care, as well as welfare systems, are examples of important societal support systems in times of need, and these are linked to each other. The health care system is one component of an individual's as well as a population's welfare. A satisfied 'need' in relation to health care does not necessarily imply the improvement of the individual's overall experience of welfare (Hamlin, 2008), but health can be considered one component of the individual's welfare (Nordenfelt, 1993).

'Welfare' per se derives from the concept of doing well (Bennett, Grossberg, & Morris, 2005) and is relevant in this doctoral dissertation because 'being well' is assumed to relate to one's own health when subjectively as well as objectively assessed. This assumption finds support in the definition of welfare by the Welfare Commission (Ministry of Health and Social Affairs, 2002): 'Welfare is defined ... in terms of individual resources that allow citizens to control and consciously steer the direction of their own lives' (p. 9). To lead an optimal life, good health is a vital resource. The Swedish model for welfare policies takes its stance from universalism, which refers to services that are offered to all citizens in Sweden in order to promote equity (Ministry of Finance, 2017).

One important welfare service that facilitates the promotion and maintenance of health and the prevention of disease is the health care system. The Ottawa Charter for Health Promotion (World Health Organization, 1986)

addresses the importance of facilitating healthier choices, and one choice that impacts the individual's health and well-being is using health services in an informed way. However, these choices are also affected by surrounding circumstances; therefore, enabling these choices can include lowering, if not eliminating, thresholds to using health services such as mammographic screening. The health care system and the services it offers can be seen as a planned attempt by the society to promote health and prevent disease to allow for longevity, which is congruent with the definition of public health (Acheson, 1988). Because the focus of this doctoral dissertation is mammographic screening and the services provided to the public to do well and strive for good health, the health, welfare and public health are acknowledged.

The overall aim of Sweden's public health policy is to create prerequisites for good and equal health in the entire population (Government Bill [Proposition] 2017/18:249). To experience health, one major determinant amongst every country's citizens is equally distributed and accessible health care. Equity in health care can be defined as 'fair arrangements that allow equal geographic, economic, and cultural access to available services for all in equal need of care' (Whitehead & Dahlgren, 2006). People's needs and opportunities, for example with a focus on improved access to health care, should be the foundation in the quest for increased equity in health-promoting and disease-preventing health care. Equity in health concerns more determinants for health that influence the population's everyday life than merely the provision of health care. Equal health care, as one determinant of many that affect the population's health, concerns an accessible welfare service (Swedish Association of Local Authorities and Regions, 2016). The complex matter of access is mainly political in its essence due to the power of government over resource allocation to even out the societal conditions between different clusters of individuals (SOU [Swedish Government Inquiries] 2017:47). This doctoral dissertation focuses on a segment of health care, namely mammographic screening, as a part of the health system that caters to actions carried out to promote, uphold and restore individuals' health (World Health Organization, 2000).

Theoretical perspectives

Two conceptual frameworks are used in this doctoral dissertation. The first is Penchansky and Thomas's (1981) framework of 'Access', which is elaborated on by Saurman (2016). This framework is relevant in this doctoral dissertation due to its focus on access to and participation in health services, with considerations to the complexity of the concept of access. The second framework, 'The Main Determinants of Health' by Dahlgren and Whitehead (1991; Whitehead, 1995), is broader in its display of determinants that affect health. These determinants can be found in all the different dimensions of access due to the nature of the determinants as present in all aspects of the individual's and population's health. In this doctoral dissertation, more focus is placed on 'the determinants of social inequities in health' (Dahlgren, Whitehead, & World Health Organization Regional Office for Europe, 2006).

These two frameworks can be used as complementary in relation to access to and participation in health care. In addition, the concept of *participation* is addressed, and in this case, mammographic screening in particular. To discuss degrees of participation, Arnstein's (1969) concept of the ladder of participation is used as a tool, not specifically in the context of the utilization of health services but in citizens' participation in decision making. The ladder is used in this dissertation because participation in mammographic screening can be at different levels, depending on whose perspective participation is viewed from. The ladder also has a community perspective.

Access

The concept of access has been addressed in several papers in relation to the health care system and its services with regard to what it means and how it can be measured (Donabedian, 1972; Frenk & White, 1992; Levesque, Harris, & Russell, 2013; Penchansky & Thomas, 1981), as well as from an equity perspective (Goddard & Smith, 2001).

In this doctoral dissertation, the conceptual framework of access by Penchansky and Thomas (1981) and its definitions and dimensions are used in a reflective manner, which defines access as 'the degree of "fit" between the clients and the system' (Penchansky & Thomas, p. 128). The idea behind the development to identify and specify dimensions within the overall concept of

access was, according to Penchansky and Thomas (1981), to facilitate potential measurable indicators for assessment of the ‘fit’.

There are five identified dimensions included in the concept of access: acceptability, affordability, availability, accessibility, and accommodation (Penchansky & Thomas, 1981). Additionally, a sixth dimension, awareness, has been suggested by Saurman (2016):

- *Acceptability* contemplates the individuals’ attitudes toward characteristics of providers in relation to the actual characteristics of the existing providers, as well as the providers attitudes regarding the characteristics of clients.
- *Affordability* focuses on financial issues, such as perceived worth in relation to costs.
- *Availability* refers to the supply of existing services and resources in relation to the individuals’ needs.
- *Accessibility* considers the location of services in relation to the individuals, with respect to factors such as travel time, distance, cost and transportation.
- *Accommodation* concerns the level of accommodating the individuals’ needs in terms of opening hours and telephone contacts (Penchansky & Thomas, 1981).
- *Awareness* addresses the importance of communication and information to understand the purpose of, as well as the ability to use the knowledge, in relation to the offered health service (Saurman, 2016).

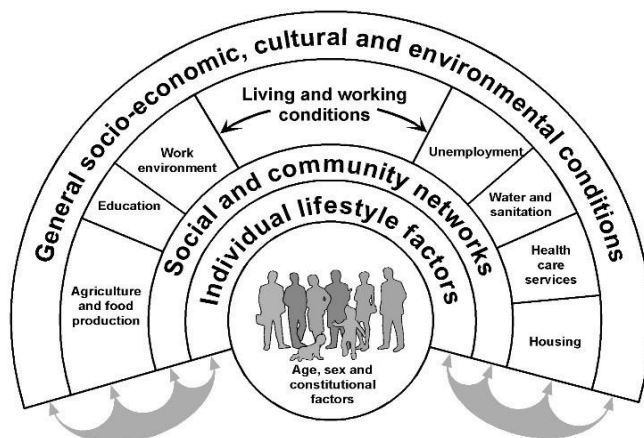
The influence of any misfitting in the dimensions may be reflected in the decreased use of the health service, lowered service satisfaction and, for instance, reduced time with patients or offers of preventive services (Penchansky & Thomas, 1981).

The Main Determinants of Health

The Main Determinants of Health (Figure 1) is a conceptual framework that is valuable within the field of public health sciences. This ‘thinking model’ was developed with purpose to offer another perspective in public health science, moving away from the dominant diseases focus to an emphasis on determinants of health. It has not been developed from a specific theory, however it has generated support for development of theories, facilitated understanding of structurally determined habits, which is influenced by for instance living and working conditions and political decisions (G. Dahlgren, personal communication, July 1, 2020). The model illustrates the ‘causes of the causes’ for health, with ‘causes of the causes’ referring to the underlying conditions

that impact the development of illness or maintenance of health and involve all the facets of where the individual spends his or her life (Marmot & Commission on Social Determinants of Health, 2007). The conceptual framework, or model, of the main determinants of health interprets different influential factors of health. It covers multiple layers including indirect and direct factors affecting the health of the individual.

The Main Determinants of Health



Source: Dahlgren and Whitehead, 1993

Figure 1. The Main Determinants of Health by Dahlgren and Whitehead (1991) (accessible in Dahlgren et al. 2006), published with the permission of the authors.

The inner circle represents individual, more or less pre-set characteristics, such as age and sex. Closest to the individual are the individual lifestyle factors such as smoking and unhealthy diets. If these factors are regarded as negative for the individual's health, they are referred to as risk factors, while the opposite is positive and protective lifestyle factors. Physical inactivity and economic insecurity would be examples of risk factors, and safety belts and vaccination are examples of protective and positive factors. Hence, lifestyle factors can be defined as healthy, protective or of risk. Politics and resource allocation, as well as budget and environmental policies, are examples of determinants that are difficult for the individual to directly influence. However, they are of great importance, as political decisions have a pivotal effect on individuals' living and working conditions and lifestyle. In the model, health care services fall under the layer of 'living and working conditions'. However, this service is dependent on resources and to a great extent financed by taxes. Available and well-educated personnel are another resource; this is

linked to educational opportunities for potential health care staff and the appeal of working within the health care system. This, in turn, also depends on competitive wages, good work conditions and infrastructure. This example explains the interactions and sometimes synergetic effects the determinants have on each other. The determinants of health work both horizontally, within each layer, and vertically between the different layers.

An inequity perspective can be applied to the economic, social and environmental factors, as they can be adjusted (Whitehead & Dahlgren, 2006), for instance via policies and the reallocation of resources. Therefore, when these determinants, in combination, result in health differences between socio-economic groups in a population, they can be labelled as determinants of social inequities in health and deemed as ‘systematic, socially produced (and therefore modifiable) and unfair’ (Whitehead & Dahlgren, 2006). Health is at stake if conditions are unfavourable for groups in society, and if these decisions are unjust, systematic and amendable, it is an expression of social inequity in health (Dahlgren et al., 2006).

Participation

To participate in something is defined as ‘partake’ (Merriam-Webster, n.d.). The word *participation* itself can be used in different contexts, and in this doctoral dissertation refers to participating in mammographic screening. To take part in something could be at a level of attending or being actively involved, engaged and with power to exert influence in an activity (Arnstein, 1969).

The component of power is emphasized as a key feature in participation (Carpentier, 2011). On the eight rungs of the ladder of citizen participation by Arnstein (1969), different degrees of participation are depicted, and the degrees relate to an element of power with an effect on an outcome. The two lowest steps are manipulation (rung 1) and therapy (rung 2), where the degree of citizen participation is labelled as being ‘non-participatory’ as the level of real influence the citizen has on an outcome is minimal. Informing (rung 3), consultation (rung 4) and placation (rung 5) allow the citizens’ views and opinions to be heard, yet not necessarily considered when a decision is about to be made. This is categorized as ‘tokenism’. The three remaining rungs – partnership (rung 6), delegated power (rung 7) and citizen control (rung 8) – are increases of power in decision making, and the voices of the citizens become stronger the higher up the ladder one climbs. The three highest degrees of participation fall under the label of ‘citizen power’ (Arnstein, 1969).

Rationale

This doctoral dissertation describes and explores access to and participation in health care. In public health, equity is a core value, which supports and enables the right of the individual to attain the highest level of health (United Nations Committee on Economic, Social, and Cultural Rights, 2000) and is a permanent variable to acknowledge when considering the impact social determinants have on health. To maintain and restore health, access to health care is a facilitator, and as stated by the European Commission, ‘Compared to the evidence that has been gathered on the socio-economic inequalities, there is surprisingly little research on the corresponding inequalities in access to health care services’ (Huber et al., 2008). There is an acknowledged need for assessment of access to screening services by the EU member states in order to facilitate comparison for potential common standards regarding cancer screening programmes. The assessment has also been requested by the Council of the European Union in its council recommendations on cancer screening. This is due to an understanding that, without knowledge of the health and social effects it has on the population, the delivery of, in this case, mammographic screening, is not defensible (Ponti et al., 2017).

Research in Sweden concerning access to health services per se is fairly sparse, and it investigates, for instance, unmet needs in relation to medical treatment, where individual financial restraints were seen as one major determinant (Fjær, Stornes, Borisova, McNamara, & Eikemo, 2017). Socio-economic status was also found to be a factor in a study regarding young adults’ (aged 16–25) utilization of general practitioners and youth clinics (Mosquera, Waenerlund, Goicolea, & Gustafsson, 2017). As noted, these studies have more of an emphasis on the impact of socio-economics and health, whereas this doctoral dissertation focuses on access to and participation in health care services, specifically mammographic screening in a region, from the public health perspective regarding disease prevention and by addressing potential inequalities. In Sweden, studies with an explicit emphasis on a specific region have mainly been conducted in the three metropolitan areas (Stockholm, Gothenburg and Malmö) and have focused on the effect of mammographic screening on breast cancer mortality (Bjurstam, Björneld, & Duffy, 2016; Frisell, Lidbrink, Hellström, & Rutqvist, 1997; Zackrisson, Andersson, Janzon, Manjer, & Garne, 2006). In addition, two counties have been followed over time to evaluate the benefit of a mammographic screening programme in relation to breast cancer mortality among the invited women (Tabar,

Fagerberg, Duffy, & Day, 1989). Another Swedish study has been conducted to examine if neighbourhood of residence has any impact on non-attendance (Lagerlund et al., 2015).

In the Swedish region of interest, no similar study has been conducted concerning the access to and participation in mammographic screening. The importance of a regional perspective is twofold. First, the regions are self-governed, and by mandate from the government are responsible for the health care and allocation of resources to issues concerning health care (Anell et al., 2012). Second, the Swedish Commission for Equity in Health (SOU [Swedish Government Inquiries] 2017:47) suggests that every region investigate non-participation in mammographic screening in order to direct relevant and effective actions to reach these groups of women whom do not participate. This is due to the importance of participating in offered screening services, and non-participation has been linked to the social determinants of health (SOU [Swedish Government Inquiries] 2017:47).

The influence this doctoral dissertation may have within the regional welfare system – as health care is considered a part of the welfare system (Blomqvist, 2004) – is in its contribution towards research and studies with a focus on the dampening or confounding factors concerning the utilization of health care. In addition, ‘cancer screening must be viewed as part of a dynamic process in which interactions take place between the individuals and the health care system in a changing social, economic and political environment’ (Chiu, 2003, p. 15). Therefore, it is important to keep updated on the situation concerning mammographic screenings at a regional level.

The results of the project can be brought back into the health care system and contribute as well as serve as a reference for more targeted interventions. In addition, the results can contribute to an increased awareness regarding the complexity of access to and participation in mammographic screening from a regional and national perspective, as well as in international contexts where similar governance of health services is present.

Aim of the doctoral dissertation

The overall aim of the doctoral dissertation is to describe, explore and understand access to and participation in health care, using mammographic screening as an example. This can provide support when formulating, developing and improving interventions and strategies to achieve more equitable health care.

Specific aims

Study I

To elucidate on three associations: between municipality and non-attendance, between age and non-attendance, and the interaction of municipality of residence and age in relation to non-attendance.

Study II

To describe the experiences and perceptions about mammographic screening of participating women from three municipalities in a Swedish county.

Study III

To gain a deeper understanding of women's experiences and perceptions about non-participation in mammographic screening in a Swedish region with only one mammographic facility.

Study IV

To describe how politicians within a region in Sweden perceive women's participation in mammographic screening and the politicians' possibility to affect participation.

Methods

To reach the overall aim of the doctoral dissertation, one quantitative and three qualitative studies were conducted (see Table 1). The first study had a quantitative design and contributed with a description of mammographic participation in relation to some sociodemographic variables in the region. The three following studies used a qualitative design and allowed for a deeper understanding of perceptions and experiences of mammographic screening from the perspective of invited women and politicians in the region.

Table 1. Overview of the four studies in the doctoral dissertation.

Study	Design	Sample/ Participants	Data collection	Analysis	Status
I	Descriptive and analytical quantitative cross-sectional	52,541 women	Register data	Frequencies of aggregated data, multivariate logistic regressions and pair-wise chi-square tests	Published 2015
II	Descriptive qualitative	27 women who have participated in mammographic screening (six groups consisting of between four and five women)	Group discussions	Qualitative content analysis	Published 2018
III	Descriptive qualitative	20 women who declined the invitation to attend mammographic screening	Individual interviews	Qualitative content analysis	Published 2020
IV	Descriptive qualitative	10 politicians from a regional subcommittee with a focus on public health and health care issues, in a Swedish region	Individual interviews	Reflexive thematic analysis	<i>Submitted to BMC Health Services Research</i>

Setting and participants

The county in focus for all four studies in the doctoral dissertation consists of 10 municipalities and is centrally situated in Sweden. The county's land area is 5,117 km² in comparison to the median of 10,554 km², which translates to the county being the third-smallest in Sweden in terms of area (Statistics Sweden [SCB], 2019). The population was 275,845 (139,089 men and 136,756 women) in 2019. For the same year, the female population aged 40 to 74, hence the subjects of invitation to mammographic screening, was 57,312 (Statistics Sweden (SCB), 2020). About 45 percent of the women reside in a municipality other than where the county's only mammographic facility is stationed. The approximate distance of the municipality furthest from that of the

mammographic facility is 80 kilometres. In Studies I, II and III, the concept of 'county' is used, as it represents a geographical area, whereas in Study IV the word 'region' is used. The reason is that there was a name change from 'county council' to 'region' on January 1, 2017 due to an increased responsibility bestowed on the counties by the government.

Study I

The sample in the study consisted of women aged 40 to 74 who were invited to mammographic screening during the years 2011 and 2012. This sample covered the total population of invited women in the county, which equated to 52,541 individuals and represented all the municipalities in the chosen county. They represented all the municipalities in the chosen county. Since the data regarding sociodemographic variables were at an aggregated level, the only individual characteristics available for the women were their age, municipality of residence and whether they had participated in the mammographic screening.

Study II

Women aged 40 to 74 residing in one of three municipalities in a county, and who had attended mammographic screening, were recruited by a form of snowball sampling (Polit & Beck, 2010). The municipalities were chosen based on the findings in Study I. One municipality displayed the highest rate of attendance, the other the lowest rate of attendance, and the third stood out because it did not reflect the potential effect distance may have on attendance rate. For each municipality, two focus groups were conducted, equivalent to a total of six focus groups and 27 participants. The median age was 60 years. Sixteen women had a tertiary education, nine achieved a secondary level, and two had a primary-level education. One woman was born outside both Scandinavia and Europe; two women were born in Europe and 24 in Scandinavia, of whom 23 were born in Sweden.

For two of the focus groups, the snowball sample was initiated via a colleague who knew a woman in the municipality of interest. In turn, this woman asked colleagues to attend. In the other municipalities, the snowball started via telephone contact with a person active within a local-interest organization, and she contacted acquaintances and members as well as suggesting the names of potential contact persons. One woman who initially accepted had to decline due to double booking on the scheduled day for the focus group. However, she found a substitute, so the number of informants was unaltered.

Study III

Women between 40 and 74 years of age in the county of interest, who had declined the invitation to attend mammographic screening on the last two occasions between 2013 and 2016 (defined as non-participants), were invited. The sampling was stratified randomly (Polit & Beck, 2010), and potential participants were identified using an invitational register maintained and controlled by the local hospital. The selection of women who met the inclusion criteria was made by administrative personnel at the hospital. To assure that all months of the year were represented, every 22nd woman with two consecutive letters 'A' and/or 'P' was selected for every month.

The letter 'A' indicates an active decline to attend the screening invitation, such as calling the mammographic unit to inform of the declination, while 'P' is a passive action of not showing up at the offered time. After the selection was made, the administrative personnel sent a letter with information about the study and a form to fill out if they were interested in participating in an interview regarding non-attendance at the mammographic screening. This form was then to be mailed back to the doctoral student, who in turn contacted the women to further investigate any interest in being interviewed. At this time, the name of the woman was revealed to the doctoral student. A reminder was sent after a month to those women who had not replied, following the procedure mentioned above.

In total, 11 women were individually interviewed. The median age was 63 years; eight of the women had a tertiary education, one a secondary-level education and two a primary-level education. One woman had been born in a country other than Sweden, while the rest were born in Sweden. The informants represented six of the county's 10 municipalities.

Study IV

Politicians representing the regional subcommittee with a focus on public health and health care issues were invited, via email, to be individually interviewed based on their knowledge and experience; hence, the sampling was purposeful (Patton, 2002). The subcommittee consisted of a total of 12 members, and 10 agreed to be interviewed. The two others never responded to the initial email or to the reminder that was emailed 14 days after the first message, nor did they answer any telephone calls. The responsibilities of the subcommittee include following the region's work with national agreements and guidelines; they can also initially make decisions about the procurement of health care services up to a value of ~ 9 million SEK (Region Västmanland, n.d.), equivalent to 863,550 euros. Of the 10 informants, six were women and four were men, with a median age of 53 years. The characteristics of the interviewees regarding their experience as politicians varied from less than a year to 19 years. Other than one who had another occupation besides politics,

all worked as full-time politicians, either in the majority or in the opposition. All informants represented a position on the regional executive committee, where six of the politicians were members of the regional executive committee and four functioned as deputy members.

Data collection

The data collection consisted of registered individual and aggregated data, focus group discussions and individual interviews.

Study I

Both aggregated and individual data were collected. The aggregated data, with the purpose to describe the municipalities' different socio-demographic profiles, were collected from the administrative agencies the National Board of Health and Welfare, the Swedish Social Insurance Agency, Statistics Sweden and the Public Health Agency. The data covered nine socio-demographic variables: labour position, highest share of low income earners (as a proxy for level of income of women), educational level, civil status, days of sick leave covered by insurance for a 12 month period (as a proxy for health), type of household, ethnicity and family size. Google Maps was used to estimate a distance between the postal address of the mammographic facility and each municipality's train station. The individual data consisted of age, postal address and information about attendance or non-attendance. These data were retrieved from an invitational register for mammographic screening.

Study II

In each of the three chosen municipalities, two group discussions were conducted with the purpose of achieving a better understanding of the experiences and perceptions of mammographic screening by women who participate in it. No informant participated in more than one group. By conducting the group discussions more than one time and with other participants, it was possible to identify patterns regarding a service (Krueger & Casey, 2015), in this case mammographic screening. Each group consisted of four to five informants, and by using this size of group, a comfortable atmosphere could be established (Krueger & Casey, 2015; Peek & Fothergill, 2009) and much information could be retrieved at the time (Peek & Fothergill, 2009). The discussion groups were conducted at a location of the discussion groups' preference and convenience in five cases (conference, coffee or lecture room at the workplace, as well as a café), and after work so there was no interference by other people. One of the discussion groups was held in a conference room at the local hospital, suggested by the person who was active within a local-interest

organization and who had been the contact person during the sampling process for three of the discussion groups. The discussions were facilitated by a moderator (interviewer) and an assistant moderator. Amongst some core responsibilities, the moderator carefully led the discussion and asked questions and probed when necessary, and the assistant moderator took notes and then summarized the discussion (Krueger & Casey, 2015).

A semi-structured interview guide was used, inspired by the ideas of Krueger and Casey (Krueger & Casey, 2015) when developing a questioning route. Before the actual focus group interviews were conducted, the interview guide was tested on four colleagues to assure that the questions were understandable and clear. Examples of questions asked during the discussion were ‘What do you think of when you hear the words ‘mammographic screening?’’, ‘How did you reason when making the decision to participate in screening?’ and ‘Which is the most important factor for undergoing mammographic screening?’ Based on the answers, follow-up questions were asked.

The length of the interviews ranged between 53 and 72 minutes. They were transcribed verbatim by the moderator (first author), resulting in 17 to 34 pages (a total of 144 pages).

Studies III and IV

Individual interviews were conducted to explore the informants’ experiences and perceptions of mammographic screening in dialogue form (Kvale, 2014). An interview guide consisting of predetermined, open-ended questions was used (Given, 2008). The interviews were conducted at a place chosen by the informant to allow for an environment of comfort.

The aim for Studies II and III was the same; however, in Study II the women participated in mammographic screening, contrary to the women in Study III. Hence, the same interview guide was used in Study III, with adjustments so that the informants were classified, based on selection criteria in the sampling phase, as non-participants. The following are some examples of the questions: ‘Think back on when you first got the invitation to mammographic screening. What did you feel and think?’, ‘What factors have influenced your decision to refrain?’ and ‘What do you think is the most important reason for you to decline the invitation?’

In Study IV, the interview locations were chosen by the informants. One interview was conducted over the telephone, two took place in a conference room at the local university and the remaining seven interviews were at a conference room or the informant’s own office at her workplace. Examples of interview questions were: ‘What do you think are the reasons why some women do not participate in mammographic screening?’, ‘How do you perceive participation in mammographic screening?’ and ‘How can you, in the position of a politician, concretely influence participation in mammographic screening?’ For both Study III and Study IV, follow-up questions were asked.

The interviews (Studies III and IV) were audio-recorded, then transcribed verbatim by the interviewer (first author). The interviews in Study III had a duration between 23 and 58 minutes and resulted in 9 to 23 pages of material (a total of 172 pages). For Study IV, the interviews lasted between 37 and 78 minutes, with a page range of 12 to 35 (a total of 214 pages).

Data analysis

Study I had a quantitative design in order to describe the participation rate in mammographic screening in the region in relation to certain variables (Creswell, 2009). Studies II, III and IV all aimed at understanding the experiences and perceptions of individuals regarding a phenomenon; hence, a qualitative approach was applied (Patton, 2002).

Study I

The analysis carried out regarding the aggregated data was the calculation of prevalence for attendance and non-attendance. For the individual data, two different analyses were conducted: multivariate logistic regressions and pairwise chi-square tests. A multivariate logistic regression is performed to determine which variables affect the probability of an event (Plichta, Kelvin, & Munro, 2013). In this study, the multivariate logistic regression analyses were conducted to identify whether municipality of residency and age were independently associated with non-attendance at mammographic screening. Pearson's chi-square (X^2) tested the potential association between non-attendance and age groups in the different municipalities (Plichta et al., 2013). Age was compared between the reference area, which is the municipality where the only mammographic facility in the county is located, and the nine other municipalities. To further analyse the associations found in the previous analyses, an interaction analysis was performed for each municipality, in comparison with the reference municipality, and non-attendance varying in relation to age.

The analyses of the individual data were performed using the Statistical Package for the Social Sciences, SPSS Statistics, version 19, by IBM.

Studies II and III

For both Study II and Study III, an analysis of the data was made using qualitative content analysis to describe a phenomenon – in this case, the experiences and perceptions of mammographic screening from the invited women's perspective – but choosing two different approaches for conducting the analysis. Qualitative content analysis, regardless of approach, is used to reduce the data in an organized manner (Schreier, 2012) by restructuring text

sections of relevance for analysis, with the purpose of identifying the essential meaning (Patton, 2002). By using these two approaches, the study facilitated progression in knowledge of the craft of conducting a content analysis by approaching the text using two different levels of interpretation: one close to the text's so-called *manifest content*, and another focusing on the *latent content*, or consideration of the underlying message [or statements] of the text (Graneheim & Lundman, 2004).

In Study II, an inductive approach according to Graneheim and Lundman, (2004) and Graneheim, Lindgren, and Lundman (2017) was performed. The interviews were transcribed verbatim, and the transcription was read through several times to achieve an understanding of the sense of the whole. Meaning units were identified and condensed, describing the content close to the text (manifest), and thereafter coded to facilitate the creation of subcategories. The subcategories were grouped into categories answering the objective of the study, resulting in four categories. To increase the credibility (Graneheim & Lundman, 2004), a co-author read through the codes and subcategories and placed these into the categories that the main author had formed. The congruence when sorting the subcategories into categories was high. Where any discrepancy where found, the main author could clearly account for the context in which the statement had been said, and a consensus between the main author and co-author concerning the choice of category was reached. In addition, by always having the aim of the study and the specific objectives in mind, the risk of alterations during the process of analysis was minimized (Graneheim & Lundman, 2004).

The analysis used in Study III was a qualitative content analysis with an inductive approach as inspired by Elo and Kyngäs (2008), with consideration of the latent content allowing for a deeper level of interpretation of the data. After verbatim transcription, the text was read through several times, before and during analysis. For each individual transcript, comments were made, initially in the margins, describing the content of text units, remembering expressions and moods, and identifying relevant open codes in order to transfer the headings into a coding sheet and translate them into categories. The next step involved a grouping of the categories based on similarities, resulting in more abstract and fewer categories. The process evolved by abstractions being made into generic and finally main categories. The whole analysis process involved reflecting on the content of the text and what it conveyed in relation to the purpose of the study.

Study IV

To 'identify, analyse and interpret patterns of meaning (themes) within qualitative data' (Clarke & Braun, 2017, p. 297) relating to the informants' perspectives and views on mammographic screening, a reflexive thematic analysis method with an inductive approach, as suggested by Braun and Clarke

(2006, 2019), was used in Study IV. The six steps were adhered to throughout the analysis process: familiarization with the data, coding, generating initial themes, reviewing themes and defining and naming themes, ending with writing the report. *Familiarization with the data* occurred when listening to and transcribing each interview, and notes were made to remember the thought process in relation to the content. This procedure allowed the data to become familiar and facilitated self-reflections concerning one's own assumptions, preunderstandings and awareness of the potential impact of findings from the previously conducted studies in the research project, while analysing the data. This reflective process was ongoing throughout the analysis. *Coding* followed the 'read-through', as codes (concise meaningful labels) were created from relevant data extracts, followed by collecting all the codes in a document to seek patterns. This step was followed by reflecting on what these patterns were 'all about', and the *generating of themes* (both initial and reviewing) entailed constantly having the research question in mind. During these phases, mind maps were created to facilitate the visualization of the thinking around the themes and subthemes, as well as coherence between the themes, to *define and name the themes and subthemes*. The final step was the *writing* of the findings in a paper, which allowed for final reflections regarding the process and the generation of themes, and consequently the overall findings.

Ethics

Ethical approval for the four studies was obtained from the Regional Ethical Review Board in Uppsala. Study I was approved on March 13, 2013, Document No. 2013/071. Studies II, III and IV were approved on October 14, 2015, Document No. 2015/393. Certain changes needed to be made for Study III regarding the specific objectives and sampling method, which resulted in a notification for amendments June 1, 2017. The amendments were approved on August 8, 2017, Document No. 2015/393.

Study I did not include any personal contact with any respondents, and therefore no informed consent was needed. For Studies II, III and IV, the data consisted of text from interviews. Before the interviews took place, the informants were given information about the purpose of the study and their rights, according to good research practice. The practice involves respect for confidentiality and de-identifying the data material, as well as providing information about the voluntary nature of participation in the interview, which at any time could be withdrawn by the informant without any explanation (Swedish Research Council [Vetenskapsrådet], 2017). This information was given both verbally and in written form, and informed and signed consent was collected from the informants, all of whom received a copy of their signed consent forms. The collected data were stored in accordance with the Archive Act (SFS [Swedish Statute Book] 1990:782). In Studies II, III and IV, the

informants were informed about the professional background of the interviewer, a registered nurse who is now a lecturer in the public health sciences. The information was given in order to be transparent in relation to the informants.

Results

Study I

The results show that in the county, the non-attendance rate varied between 17.6 percent and 24.4 percent. The reference municipality (18.0 percent non-attenders) where the mammographic facility is located did not display the lowest non-attendance rate. The reference municipality had a better socio-economic profile than the municipality that had the lowest non-attendance rate (17.6 percent). The municipality with the lowest non-attendance rate, situated 20 to 39 kilometres from the reference municipality, displayed the lowest percentage of women with a higher education (an educational level of more than 15 years) in comparison with all the other municipalities in the county. However, more of the inhabitants owned or had a right in a co-operative building, and there were fewer low-income-earning women than in the reference municipality. The municipality with the highest rate of non-attenders in mammographic screening (24.4 percent), located 60 to 79 kilometres from the reference municipality, also displayed low scores in relation to socio-economic indicators. For instance, it had the third-lowest percentage of women with a higher education in relation to the other municipalities, while in terms of ownership/right in a co-operative building and share of low-income-earning women, the municipality placed more or less in the middle of the 10 municipalities. The attendance rate decreased in all municipalities situated >40 kilometres from the reference municipality. The rate of attendance increased with age. However, this association was not as strong for four of the municipalities. Additionally, variances were found for most age groups regarding municipality and declining the invitation to attend the screening.

Study II

The findings based on the group discussions with women who participate in mammographic screening generated four categories with nine subcategories. The categories are marked using quotation marks, and the subcategories are in italics.

The first category is 'insecurity surrounding the screening procedure', reflecting events before, during and after the examination itself, and covers, for instance, the actual physical procedure and meeting with the staff as well as

the feelings that emerge from this. The participants shared *thoughts and feelings concerning examination*, where the undressing, handling of the breasts by unknown staff and contact with the cold machine were experienced with different levels of discomfort. For most of the participants, the *uncertain waiting* regarding the results was a source of tension. *Lack of information* about the expected time to receive the results, reasons for the age limit for being invited and inconsistent information also caused confusion, and a certain amount of distrust in the screening was expressed.

‘Participation as a norm’ addressed the *impact of other people’s stories and opinions*, which the participants expressed could influence a woman who is invited for the first time about whether to attend. Stories that convey a negative experience, as well as positive encounters, inherited norms and cultural beliefs, all influence the decision. Most of the women themselves displayed some expression of a norm that promotes participation. Regarding cultural circumstances, a lack of mammographic screening facilities and national screening programmes may also explain the willingness to attend. The *understanding and prioritization regarding attendance* are articulated, as all the women agreed that early diagnosis and commencement of treatment are pivotal for the decision to attend. The importance of attending mammographic screening could be understood; however, conflicts can arise in prioritizing due to lack of time, and it is occasionally substituted with self-examination of the breast.

The participants discussed ‘required and recurring planning’, where *practical issues and alternative solutions*, such as getting time off from work, traveling expenses and inconveniences in relation to the planning of the visit were covered. The distance to the screening facility was an issue due to the inconveniences it poses. The previous solution with a mobile unit was seen positively by most of the participants; however, the recall rate was perceived by some of the participants as higher when the mobile unit was used. Residing further from the screening facility involves added costs, both indirect and direct, which is reflected by *the importance of finances*. The ‘gratitude and respect for mammographic screening’ category was seen from a service perspective as *an appreciated benefit*, both the invitational aspect and the mammographic screening service itself, and one to be utilized. Some of the participants suggested promoting this more amongst friends and colleagues as one way to shed light on the importance of attending. The *awareness of the value of mammographic screening* was also expressed, as the participants agreed that it saves lives and affects not only the individual but also the extended family.

Study III

The findings from the interviews with the women who, at least in the two most recent invitational rounds, chose not to participate in mammographic

screening include experiences and perceptions regarding the set-up of mammographic screening, their own reasoning to refrain and structural barriers difficult to affect. 'Doubts regarding mammographic screening and its organization' were articulated by the informants when reflecting on mammographic screening. The apparatus is a cause of frustration, as it is perceived that there is an alternative apparatus that is less painful but not procured. In addition, concerns around the procedure when taking the actual mammogram, such as the level of radiation and the reliability of the mammogram, were mentioned. Ambivalence was expressed through the coexistence of perceptions of distrust and appreciation for being invited to the mammographic screening. To be invited is an appreciated benefit, and to accept the invitation is highly advocated for by the informants; however, this applies when it concerns other persons, such as friends and relatives. Appreciation is also expressed concerning the staff, yet the procedure itself is perceived as impersonal.

Both 'sense and sensibility in the decision to refrain' from mammographic screening play a role for the informants. Sensations of pain, fear of what the mammogram may show and conflict between the perception that 'one should attend' and the action to refrain from mammographic screening are reasons that are reflected upon and coped with in different ways. Through trust in one's own body, family history regarding causes of death and a perception of intuitively knowing if something is wrong, through which the decision to refrain is, in a way, validated.

To refrain from the screening is also related to experiences of 'dependency and options'. The findings relate to individual circumstances, the set-up of the health care system from the perspective of service-mindedness such as opening hours, offering options to cater to the woman's articulated need, and the physical accessibility to the screening facility, in order to facilitate participation in mammographic screening

Study IV

The findings from the interviews with the politicians resulted in two main themes: 'expected actions' and 'prerequisites for acting'. A high participation rate for mammographic screening is important to all the informants, and certain expected actions, which concern both the invited woman and the politicians as decision makers, are perceived as important. According to the informants, the acquisition of information upon which to base the decision, such as the purpose of the mammogram and the process, is important for the women; for the politicians, it is equally important to keep updated regarding participation rates and trends. A commitment to health is shared between the individual and the health care organization (here represented by the politicians), and the informants expressed that the individual must take responsibility for her own health, which can include, if not participating in mammographic screening, at

least conducting breast self-examinations and getting to know one's own body in order to act if something is wrong.

For the organization, the commitment to health is linked to lowering thresholds for individuals to take responsibility for their health. The thresholds can relate to making it easier for women to access the facility, catering to the need for information that is easy to understand, communicating how to navigate through the screening procedure and helping the women to feel comfortable when undergoing the mammogram. In addition, the importance of politicians making themselves available to answer questions and have a dialogue concerning women was also expressed. However, the action requires certain conditions to be met in order to be relevant and involves understanding the reasons why women refrain from mammographic screening. All the informants partly or wholly addressed the impact socio-economic position (encompassing the triad of education, profession and income), geographic location, ethnicity and culture have on participation in mammographic screening.

Understanding the underlying factors that influence decisions to partake in screening, or for that matter other health services, will facilitate taking conducive actions. Here the availability of resources was mentioned, not only in economic terms but also regarding staff and levels of ambition or will. A knowledge of the impact social determinants have on participation in screening was expressed by every one of the informants, and socio-economics, culture, ethnicity and geographic location were mentioned as common denominators.

Summary of findings

The findings from all four studies regarding access to and participation in mammographic screening involve both individual and structural conditions, which also may pose challenges for the individual and the regional politicians responsible for public health and health care.

Study I displayed a difference in participation rate between the municipalities. Distance to the mammographic facility had an impact on participation. In general, participation in mammographic screening increases with age. Studies II and III found that the facilitators and barriers to participation in mammographic screening are similar for women who do participate and women who have participated but then, for various reasons, choose to refrain. These challenges consist of the whole process that mammographic screening involves, from receiving the invitational letter, to taking the actual mammogram at the mammographic facility, to receiving the letter with the result of the mammogram. Generally, all women in the studies express gratitude for being invited, and most perceive it as a benefit and understand the purpose of the mammographic screening. Some doubts are expressed concerning potential harm that taking the mammogram could cause. However, obtaining a mammogram is something most of the women advocate, even the women who have chosen to decline the offer. The decision to accept or decline involves planning that is often attached to a priority-setting component. Competing interests are, for instance, taking time off work, which can cause inconveniences, and transportation to and from the mammographic facility, which is both time-consuming and costs money. These factors mirror structural conditions such as infrastructure, location of the facility and financial support when taking time off work to partake in the screening; this is perceived as being beyond the direct control of the women and is a source of frustration. The individual reasons for participating are the potential early detection of cancer; however, the pain experienced during the mammogram, the anxiety in waiting for the result and the feelings of being exposed and not considered as a person with her own needs, which the staff can at least try to accommodate, can lead to the decision to refrain. The decision to refrain can also be based on reasons of knowing one's own body and family history of cancer.

In Study IV, politicians shared their perceptions concerning mammographic screening. In this study, it is clear that mammographic screening as a diagnostic method is important and that a high participation rate is something

to strive for. Expectation for actions is expressed by the informants (politicians) for both the women's and the politician's sides. For the women, this expectation concerns making well-informed decisions regarding one's own participation based on one's own information seeking. For the politicians, it requires keeping updated about the participation rate and other issues around mammographic screening that may affect participation. A shared commitment to health entails the women taking responsibility to safeguard their own health. For the politicians, it concerns lowering the potential thresholds to facilitate the women preserving their health. For these expectations to be met, certain prerequisites are needed and involve understandings of determinants that influence the decision to refrain in order to take actions that are relevant and efficient, as well as having resources to back up these actions.

Discussions

This section includes a discussion of the results in relation to previous research and the conceptual frameworks presented in this doctoral dissertation. The overall aim of this doctoral dissertation was to describe, explore and understand access to and participation in health care, using mammographic screening as an example. The research in relation to the two areas of health and welfare, and for which mammographic screening as a health service, can be placed at their intersection, is reflected on through the discussion. The health of the individual, as a member of the society is reliant on different resources, such as the welfare service, and in this doctoral dissertation the welfare service is represented by the health care system. The health care system should be responsive to its citizens' different levels of needs (Diderichsen et al., 2012), and in this instance, facilitating for participation in mammographic screening to achieve the welfare of the individual. The facilitators can be traced to different dimensions of access and the social determinants of health, which is a core conceptual framework to understand public health. When planning an activity to improve public health, such as mammographic screening, consideration should be taken regarding the impact access to a health service and the determinants have on the decision to participate. By doing so, the individual is also enabled to take responsibility for his or her own health.

The following section is divided into different perspectives. First the individual perspective is addressed, followed by the organizational and societal perspectives.

The individual perspective

The individual perspective refers to determinants such as age and socio-economic status. In addition, values and norms are placed under this perspective, even though these are highly influenced by the social group and community with which the individual is associated.

The main findings indicate that age and residence of municipality may have an impact on attendance at mammographic screening (Study I). To be older, in comparison to the age group 40–44, was found to be associated with accepting and complying with the invitation to attend, which is supported by some other studies (Larsen et al., 2020; Ozmen et al., 2011). However, the reference age group in these studies differed, as Ozmen et al. (2011) compared

women in the age group of 40–49 with women 50–69. A study by Larsen et al. (2020) showed that women older than 64 years attended to a higher degree than women between 50 and 64 years of age. Some studies have found the opposite effect regarding age, wherein older age has been linked to non-participation in mammographic screening (Flytkjær Jensen et al., 2012; Siahpush & Singh, 2002). The inconclusive findings regarding age as a predictor for participation may relate to, or act in combination with, other factors, such as support systems (Flytkjær Jensen et al., 2015) and social norms (Othman, Kiviniemi, Wu, & Lally, 2012; Taymoori, Moshki, & Roshani, 2014) in the specific community which the women in the different studies represent. These suggestions offer alternative reasoning and can be reflected upon. However, age as a determinant is important to consider in participation in mammographic screening, since the life expectancy has increased and may impact mobility. In this doctoral dissertation, four municipalities did not display as strong an association between older age and increased participation in mammographic screening as the other municipalities in the county (Study I). This could be a matter of inequity in health if it is a systematic pattern and due to adjustable social determinants (Whitehead & Dahlgren, 2006) in these municipalities.

Being older may also affect the ability to handle and keep updated with new technology and all the quick changes technological innovation may bring. A report investigating American seniors' (above age 65) technology use, such as smart phones and the Internet, found educational and income levels as some of the determinants (Pew Research Center, 2014). In combination with a potentially weakened support system, as the support system has been found important in facilitating the adoption of technology (Lee & Coughlin, 2015; Pew Research Center, 2014), this could pose a risk of missing out on important health information as well as the use of digital services offered by the health care system, such as rescheduling appointments for mammographic screening.

In addition, not being used to seeking information, for instance via the Internet, or evaluating the massive information flow regarding mammographic screening may, to a greater or lesser extent, pose a challenge. The 'information society' offers information based on everything from scientific facts to personal opinions. The acquisition of information as an expected action (Study IV) requires an understanding and assessment of information in order to be meaningful. Studies have shown that originating from a different country (Jack et al., 2014; Flytkjær Jensen et al., 2012), lack of proficiency in the language spoken in the country of residency, and being used to other cultural norms (Adunlin, Cyrus, Asare, & Sabik, 2018) can be barriers to understanding health information. To prevent increased inequity in health requires that information be accessible, which could alleviate insecurity surrounding the screening procedure (Study II) and doubts regarding mammographic screening and its organization (Study III). This is valid not only for older age groups but for all women invited to mammographic screening.

Besides age and access to information, the socio-economic status of women has also been linked to participation in screening (Damiani et al., 2012; Edgar et al., 2013; Zackrisson et al., 2004), as has ethnicity (Jack et al., 2014; Renshaw et al., 2010). An understanding of the link between non-participation in mammographic screening and socio-economic status was expressed (Study IV), and a potential influence of socioeconomic position, which includes education, housing characteristics, income and occupation (Galobardes, Shaw, Lawlor, Lynch, & Davey Smith, 2006), could be reflected upon in Study I, as socio-demographic characteristics for each municipality in the county were described. Neither socio-economic status nor the influence of educational level on participation in screening was investigated in depth in this doctoral dissertation, but all levels of education were represented by the informants in Studies II and III. Educational level, which is also a social determinant of health (Dahlgren et al., 2006), includes the ability to read and write, so-called *fundamental literacy* (Zarcadoolas, Pleasant, & Greer, 2005), which can be linked to *health literacy*, referred to as follows:

People's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course. (Sørensen et al., 2012, p. 3)

The definition of health literacy by Sørensen et al. (2012) addresses the motivational factor, and values are important drivers of motivation regarding attitudes and behaviour (Schwartz, 2012). If the norm in a society prescribes women to participate in mammographic screening and is assessed by the individuals of a community or the state as a desirable behaviour, this could presumably influence the 'acceptability' dimension (Penchansky & Thomas, 1981) of the mammographic screening as a health service. The 'acceptability dimension' is, in turn, influenced by the 'awareness' dimension, which addresses the information and knowledge aspect of access (Saurman, 2016). The dimension of 'acceptability', which concerns attitudes toward the mammographic screening, here a proxy for the provider, is also expressed by the informant's perceptions of the value of the service offered (Studies II and III). These values create the backdrop for the norms, and in this doctoral dissertation it can be seen as an articulated norm that women 'should' partake in mammographic screening (Studies II, III, IV), since it is a benefit (Studies II, III) and a privilege offered by the state (Studies II, III). Even women who do not participate generally think that other women should participate, even though they have decided to refrain (Study III). In Study II, the 'acceptability' resulted in participation, while the opposite situation occurred in Study III. The appreciation of the service of being invited every second year and offered a mammogram was expressed in both Studies II and III and finds support in a study

that found that being invited was one reason for participating in mammographic screening (Willis, 2008). The invitation, sent from the mammographic facility and the health care organization, can be perceived as a representative for the state. This issue of who is the sender of a message has been discussed in relation to the implication this may have on the women's feelings of ambivalence in their decision to refrain from screening. The decision to not participate may collide with the perception of the expectation that they should participate, since the state and society endorse it (Manjer et al., 2016).

When considering the content of information when making a decision to participate in screening, studies have addressed the importance of giving information about the benefits and harm of the screening (Hersch et al., 2018; Sagan et al., 2020) when sending the invitational letter. On the basis thereof, the decisions may already have been made, as a study highlighted the impact of preconceptions formed based on information from family and friends. The study showed that the information provided when first invited, including the benefits and harms of screening, was not the predominant source of information in the decision-making process (Henriksen, Guassora, & Brodersen, 2015). This is important to consider, as the interactions between family, friends and colleagues involve exchanges of information. Being subjected to other people's experiences, beliefs and attitudes may also form an understanding of things that one might not yet have experienced. This indicates the importance the social network may have as being the primary source of information, on which, in turn, the decision to participate (or not) in screening is based. Even though the primary source of information might be a friend or other social contact, this does not make the information from the health care organization redundant; rather, it poses a challenge for the health care organization to communicate correct and accessible scientific information from which women can make their decisions.

The organizational and structural perspectives

The health care and welfare systems can be viewed from a structural perspective, being structures with their own internal organizational systems, as well as representing the social determinants of health at a level further from the direct control of the individual. The experiences and perceptions of mammographic screening, regardless of whether they are from the women's or politicians' perspective, can all be traced back to the determinants of health. The dimensions in the concept of access can also be associated with Dahlgren et al. (2006) model of the Main Determinants of Health, where the upper layer represents, among other aspects, general socio-economic conditions. These conditions are mainly controlled by the government and delegated to other institutions and public organizations, for instance the regions, in forms such as resource distribution, which can result in, for example, increased

geographical access to health care facilities. The layer 'living and working conditions' reflects the possibility to participate in mammographic screening during work time, and the layer that characterizes the 'social and community networks' may be a representation of the value of a service that the 'accessibility' dimension covers (Penchansky & Thomas, 1981).

The results regarding the influence of residence of municipality on non-participation in mammographic screening (Study I) are corroborated in a systematic review that investigated urban and rural differences in participation in mammographic screening. The review found that residing in more rural, rather than urban, areas was linked to non-participation (Leung et al., 2014). This may partly be explained by the accessibility of the screening facility, which is one of the five dimensions in the concept of access (Penchansky & Thomas, 1981). Study I investigated non-participation in mammographic screening in different municipalities, and since there is only one screening facility in the county of interest, the distance to the facility was also taken into consideration. The analysis showed a decrease in participation rate for all the municipalities situated farther than 40 kilometres from the reference municipality (which was also the municipality where the mammographic facility is located). The influence of distance has been found in other studies as well (Guillaume et al., 2017; Leung et al., 2014); however, different kilometre thresholds have been proposed as the cross-over point (Huang, Dignan, Han, & Johnson, 2009; Jensen et al., 2014; St-Jacques et al., 2013). When not using a reference municipality, the findings show that between the different municipalities in the county, a higher participation rate is displayed for a municipality situated 20–39 kilometres from the municipality where the mammographic facility is located than for the municipality with the mammographic screening facility (Study I). The findings in Studies II and III also indicate that distance per se is not a single reason not to participate in mammographic screening. In Study II, the informants represented three different municipalities with a distance between 20 and 80 kilometres from the municipality where the mammographic facility is located. In Study III, the informants represented all the different distances, from residing in the municipality where the mammographic facility is located to residing 80 kilometres from the facility.

When considering the findings from Studies II and III, the question arises of what other factors impact the decision to participate in the screening. The women in these two studies represent participants (Study II) and non-participants (Study III), and both these groups account for similar experienced barriers; however, the difference between them is the decision they have made regarding participation in mammographic screening. One explanation can be access to a vehicle, which has been found to facilitate participation (Flytkjær Jensen et al., 2012), or other means of transportation that is 'available' (defined as existing in relation to the need), and 'accessible' (by not being too costly) (Penchansky & Thomas, 1981), such as public transportation. The access to a vehicle, not investigated in this doctoral dissertation, or utilization of

other types of transportation can be linked to the ‘affordability’ dimension in Penchansky and Thomas’s (1981) conceptual framework regarding access. Even though the affordability dimension originally refers to the prices of the service, such as the fee for the examination, in relation to the individual’s estimation of worth related to the cost, the additional cost for transportation may be taken into consideration when the individual is making the decision about whether to partake in mammographic screening. This can also be linked to the socio-economic situation of the individual. The socio-demographic characteristics of the municipalities (Study I), even though not offering any concrete explanations for non-participation in mammographic screening, allow for reflections such as whether a low income or renting instead of owning a house affect participation. Or is it degrees of trust in the organization and the technology (Studies II and III) that impact the decision of whether to participate?

The ability to retrieve and assess information is important when making a well-informed decision, such as the decision to participate in mammographic screening. The information concerning health and support towards the health literacy of the population can be said to rest on the state as a guardian of the human right to health. There is also an obligation for the individual to improve their level of health literacy in order to promote their own health and prevent illness, (Sarvimäki & Stenbock-Hult, 2014) as a being member of a society. Both the state and the individual are responsible for the health, as supported by the findings in Study IV, which refer to a ‘shared commitment to health’. This understanding of a shared commitment is rooted in the general culture of the society by the shared perception of health and welfare (Ministry of Health and Social Affairs, 2002; Nordenfelt, 1993). The awareness that may affect the decision to participate in the screening requires, however, an opportunity for the individual to retrieve information and understand it (Study IV). To comprehend different aspects of information and how to practically use it in contact with the health care organization reflects the dimension of awareness suggested by Saurman (2016). It is therefore also a responsibility of the health care organization, seen in the perspective of its capacity as a social determinant of health, to facilitate for the understanding and usage of health services. Access to understandable information about health is needed for individuals, as well as the population, to become active participants in their own health (World Health Organization Regional Office for Europe, 2013). In Study IV, reflections were made by the informants (the regional politicians) regarding the challenge to reach women who are not participating in mammographic screening. Understandings of factors that influence women’s decisions regarding participation in mammography screening were perceived as facilitators for the informants to take appropriate actions. Suggestions for actions were, for instance, information campaigns to increase women’s understanding of the purpose of mammographic screening.

Facilitating a well-informed decision requires information that is neutral, concise, easy to understand, updated and repeated. In Sweden, it is optional

for every region (J. Ramos, personal communication, June 22, 2020) to use suggested templates from the Regional Cancer Centres when inviting and reminding women to participate in mammographic screening. The very first invitation, when a woman turns 40 years of age, consists of not only information about time, date, contact details, the purpose of screening and how the examination is done but also answers to some common questions, such as about benefits and harms. Since this extra information is only given with the first invitation, it could be assumed that the insecurity regarding the screening procedure (Study II) and ambivalent appreciation for mammographic screening (Study III) may have been addressed if this additional information is provided in every invitational round. Offering the service with recurring extended information would then improve awareness, as this dimension emphasizes the importance of facilitating the understanding of a health service (Saurman, 2016), and facilitate a more well-informed decision, given that both benefits and harms are accounted for. This is important, as merely receiving the invitation, without additional information, can be perceived by the invited women as more or less compulsory and not as a proposal (Hersch et al., 2018). The perception of participation in mammographic screening as compulsory can also, besides the formulation in an invitational letter, be due to how participation in mammographic screening is perceived almost as a norm in the society. The potential feelings that not participating can evoke, if the reasons are due to, for instance, socio-economic determinants, an additional psychological burden placed on already vulnerable groups in society, which then contributes to even more inequities in health. Counteractions to this could be more neutral, accessible and easily understood information, with possibilities to contact some form of ‘health support’ when making decisions, to assess the information given. Adopting a more people-centred care approach (World Health Organization, 2016) must, amongst other aspects, ‘actively involve and empower the people it is serving – both on an individual and collective level.... it promotes promoting health literacy ... and active participation on all levels’ (Maeseneer et al., 2012, p. 612). More neutral, accessible and easy-to-understand information with a possibility of ‘health support’, in combination with a people-centred form of care, could then increase a feeling of empowerment, which includes a capability to participate wherein participation represents actions, for instance decision making (Holcombe, 1995). Regardless of whether one decides to participate in mammographic screening, the decision is well-informed and owned by the individual and not the state.

The women who participated in Study II perceived certain potentially aggravating factors for participation, for instance the discomfort in the encounter with the personnel during the examination itself. Studies examining barriers to participation in screening have accounted for similar reasons, such as a feeling of disrespect during examination (Johansson & Berterö, 2003) and being exposed in front of an unknown person (Sarma, 2015), and therefore it is important to acknowledge that participants may be potential non-participants if

the barriers become too difficult to overcome. This was to some extent corroborated by the findings in Study III. These women, who declined the invitation to mammographic screening, had all at least participated in mammographic screening on one occasion. It has been found among women who continue to participate in screening that some degree of normalization occurs with time, regarding, for instance, the feelings connected with waiting for the results of the mammogram (Solbjør, Skolbekken, Østerlie, & Forsmo, 2015). This may perhaps offer one piece in the jigsaw puzzle as to why some women continue to participate even though they express the same types of barriers to participation in mammographic screening as the non-participating women. If the decision to refrain has been taken after the first invitational round due to some negative experience during the screening process, the normalization may never occur. The decision of the women to participate differed between the women in Studies II and III, where the women in Study II had decided to participate in mammographic screening and the women in Study III did not participate. The reasons for this can be several, such as a lower level of social support, which has been found as a reason to refrain from screening (Documet et al., 2015; Flytkjær Jensen et al., 2015). Even though the encounter with the personnel might not be considered as falling directly under social support, a form of support is given in the form of the responsiveness towards the needs of the woman. Some of the women (Study III) perceived the unresponsiveness from the provider as difficult to overcome, which directly influenced the decision not to participate in screening, which was also found in other studies (Johansson & Berterö, 2003; Manjer et al., 2016). The great importance of attentive personnel who can cater to women who experience fear of what the mammogram may detect, fear while waiting for the result, fear of pain or other worries are supported in previous studies (Manjer et al., 2016; Marmara et al., 2018; Watson-Johnson et al., 2011).

Reflection on the dimensions of access in relation to participation in mammographic screening can enable an understanding of important factors that can facilitate or hinder the willingness to participate. The previously mentioned support systems, such as transportation and accessible information via, for instance, the Internet, also relate to the social determinants of health (Dahlgren et al., 2006) from the general political and socio-economic level in society. For example, transportation can be seen as facilitating social inclusion, as it may facilitate access to a health care service (Social Exclusion Unit, 2003). In the county of interest in this doctoral dissertation, accessibility is part of the regional strategy for a sustainable county, with different objectives expressed and where, for instance, transportation systems such as buses or a built-out digital infrastructure within the county are part of the strategy (Region Västmanland, 2020). Besides being members of the subcommittee for public health and health care, many of the politicians in Study IV are members of other committees within the region, with opportunities to influence decisions relating to other domains such as transportation. The regional strategy

for a sustainable county can be perceived as a resource in the form of an expressed will to act, not only to improve conditions for the residents in all the municipalities in the county but also to facilitate women's participation in mammographic screening, if that is the politicians' wish (Study IV). The strategy is a conscious act to also address differences in resources which, if not acted upon, can result in inequities in health among certain groups in the county. The intention of the strategy has not been specifically to facilitate participation in mammographic screening, but by addressing, for instance, access to digital infrastructure, better public transportation and available as well as easily accessible information, the facilitation of participation in mammographic screening, regardless of socio-economic status, can be achieved.

Trust and power

The categories (Study II), main categories (Study III) and themes (Study IV) can be placed under two suggested labels; 'A Matter of Trust' and 'The Power of Power' since there are linkages between the findings, and where power and trust are proposed as support structures to the core concepts referenced in this doctoral dissertation. Experiences and perceptions revolving around the screening procedure, such as information about the purpose; the 'before, during and after' of the event in relation to the mammographic facility's level of accommodation of individual needs through sensitivity to their expressed feelings; and both the mammographic facility staff and the politician's acknowledgment of the women's voices reflect the suggested label 'A Matter of Trust'. A trust that can be derived from the personal encounter with the health care system, and in specific the mammographic screening facility, when being heard and listened to, and a distrust that is reflected in the act of not participating and feeling unacknowledged regarding personal needs and structural conditions that are potential threats (Study II) and factual barriers (Study III) to participation in mammographic screening. This trust can also be interpreted as being addressed in Study IV, expressed as the trust in the expectation that commitment to health is a shared responsibility. To have expectations of someone has an embedded element of the trust itself.

The other suggested label deals with 'The Power of Power'. Power is part of participation (Carpentier, 2011) and the ability to act, regardless of whether it involves planning to participate (e.g., taking time off work, making travel arrangements) in the screening or knowing how to navigate the system effectively (e.g., planning relevant activities) and consequently making a well-informed decision based on knowledge. The knowledge is important for both the invited women and the regional politicians (Studies II, III, IV) and can concern, for example, the purpose of the screening, body awareness, the characteristics of those who refrain from mammographic screening and influential factors behind decisions to refrain. Power also includes resources such as

financial assets, ambitions/will and personnel/support (Studies II, III, IV). The experiences and perceptions of trust and power that the findings in this doctoral dissertation reflect are not an issue of 'either you have, or you do not', as this can differ in strength depending on the context, not only between individuals but also for the individual depending on the situation.

The findings in Studies II, III and IV all address participation. It is noteworthy that two of the papers in this doctoral dissertation use different words when addressing participation (Studies I and III). In Study I, it is impossible to refer to participation as more than non-attendance due to the use of a quantitative approach. In Study III, the use of 'non-participation' has a dual meaning: non-participation as refraining from the actual mammogram, and non-participation in the sense of the perception of not being heard, but which is noted in the encounter with the health care organization (Arnstein, 1969). However, power can be exerted by the action of not taking the mammogram and can be assumed to be the case for some women (Study III).

Even though the different rungs of participation address citizens' participation in decision making (Arnstein, 1969), a relation to the findings from the three qualitative studies in this doctoral dissertation can be reflected upon for the stages of the mammographic screening process. Participation in relation to mammographic screening can be more than just attending the examination; however, it requires an open mindset to the concept of participation.

The decision to participate in mammographic screening can require different degrees of participation, from just accepting or declining the invitation to actively reading up on information and assessing the information before making the decision, not showing up at the given time or actively contacting the mammographic facility to decline the appointment, passively accepting that a service such as the mobile unit has been taken out of use, or trying to act to get the service back by contacting the region or the mammographic screening facility, and its representatives. The individual is part of a group, and the society is affected by the decisions he or she makes; some decisions are more important to be actively involved in, as the existence of a service depends on people using it.

The realization of access in all its dimensions is conditioned upon the determinants of health. It could be assumed that fewer barriers to a health care service such as mammographic screening results in a higher participation rate. However, it has been asserted that 'proof of access is use of service, not simply the presence of a facility. Access can, accordingly, be measured by the level of use in relation to "need"' (Donabedian, 1972, p. 111). However, it is important to note that, contrary to this notion, the experienced need can be present – yet due to experiences or perceptions of health care that is unresponsive to the need (Study III), the use of the service is not realized. In addition, participation, as a proxy of power, can be considered a gatekeeper to an outcome that promotes health and prevents disease. Both of these public health approaches will contribute to the welfare of the individual as well as the state.

Even though the findings in this doctoral dissertation cannot claim to be proof of inequity in health care, there is a need to reflect on the relationships between the different concepts and findings, which can indicate that inequity may be present. The informants (Studies II and III) in this doctoral dissertation all, to a greater or lesser extent, address geographical location as influential to access the mammographic facility; socio-economic conditions and knowledge have also been articulated as having an impact on the decision to participate in mammographic screening. This correlates with what inequity in health care can involve – for instance, unequal ‘geographic, economic and cultural access to available services for all in equal need of care’ (Dahlgren et al., 2006, p. 7). The informants (Studies II and III) came to different decisions about participating in screening, which may be due to other circumstances that can only be reflected upon. If the determinants are favourable for promoting, maintaining or restoring health, they are resources. These resources can be linked to distributive justice, which is the backdrop of social justice, which addresses, amongst other issues, a just distribution of benefits in relation to public health (Beauchamp, 1976). In addition, if respecting the notion of equal health care, and with an understanding that participation in mammographic screening may affect the extent of care because of the detection of abnormalities before any clinical symptoms occur, the findings in this doctoral dissertation indicate inequity in health care. It could be reflected upon if an endeavour to make women from more socio-economically disadvantaged groups participate to a higher extent in mammographic screening results in equity in health. If the decision not to participate in mammographic screening is based on factors that, if favourable, would have resulted in a decision to participate, then social inequities in health (Dahlgren et al., 2006) would be present. This is because social equity in health is conditioned by determinants other than the health care sector alone. Consequently, if these other determinants are adjusted, allowing for the decision to be made from a more equal playing field, then – as social determinants affect other parts of life beyond participation in mammographic screening – the probability that this would benefit other dimensions of life that also affect health is not inconceivable.

Methodological considerations

This doctoral dissertation takes its stance from a pragmatic view of the world, as it focuses on the research problem and uses both qualitative and quantitative research methods to obtain breadth and depth in understanding access to and participation in mammographic screening. Inspired by the procedure of sequential mixed methods, which means ‘the researcher seeks to elaborate on or expand on the findings of one method with another method’ (Creswell, 2009), Study I used a quantitative method to describe mammographic screening from a regional perspective, followed by qualitative approaches (Studies II, III and IV) to further explore different aspects of the subject.

Regarding Study I, there were limitations due to access to individual data. As a result, the analysis could only be performed on three variables: age, municipality of residency and participation/non-participation. The additional data consisted of aggregated data retrieved from Statistics Sweden. With this said, the data enabled some description of the region and the participation rate in mammographic screening, serving as a backdrop and offering guidance for relevant questions to investigate further in the upcoming studies.

Study II used focus groups to collect data and snowball sampling (Patton, 2002), resulting in a fairly homogenous group of participants with regard to educational background, workplace, work description and ethnicity. This can be a cause of bias in terms of the representativeness of the sample (Polit & Beck, 2010). This was taken under consideration, but to cancel groups because of not being more representative can be seen as unethical towards the women who wanted to share their experiences. Based on ethical considerations and due to the representation of women from three different municipalities, with different work descriptions between most of the groups as well as age distribution, the focus groups were conducted. Homogeneity is not necessarily negative, as it can also allow for a more relaxed environment when addressing potentially sensitive matters (Krueger & Casey, 2015). By using a semi-structured interview guide following Krueger and Casey’s question route (2015), the dependability could be strengthened.

The recruitment of informants for Study II had been shown to be difficult, especially without assistance from the regional mammographic facility, which at that point in time was declined for some reason that was not fully explained. Therefore, the study used snowball sampling. For Study III, help from the mammographic facility was available, and the selection of informants for Study III was done by systematic sampling (Polit & Beck, 2010) and carried

out with assistance from personnel from the regional mammographic facility, which assured the anonymity of the women up until the women themselves made contact with the researcher in charge of conducting the interviews.

Both Studies II and III used qualitative content analysis as the method for analysing the data (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004; Graneheim et al., 2017), but adhering to two different variants. The thought behind this was to get acquainted with two different ways of conducting a content analysis, which was not in conflict with the aim of the respective study. In addition, since the data collection differed, it could allow different variants to be applied more easily. If the data collection would have been the same, and with a clear intent of searching for differences and similarities between the two groups of informants (participants and non-participants), it would have been called for to use the same variant to facilitate comparisons. In Study IV, reflexive thematic analysis (Braun & Clarke, 2006, 2019; Terry, Hayfield, Clarke, & Braun, 2017) was the chosen method, for which the reflexivity of the researcher is of the utmost importance. To be transparent regarding one's own preunderstandings and professional background within the health care system and aware of the influences this exerts in the interpretation of the data, has been addressed by writing notes for the memory. By choosing suitable quantitative methods of analysis for describing certain aspects of the county in relation to participation in mammographic screening, and applying a qualitative approach to capture individuals' experiences and perceptions of mammographic screening, both breadth and depth have been offered in relation to mammographic screening.

By applying different methods of analysis in the three qualitative studies, a progression of learning could be facilitated, as well as to be acquainted with different ways to analyse data. In Study II, an inductive content analysis at a manifest level was performed, while in Study III the analysis was made on a latent level. Study IV applied a reflexive thematic analysis, where the preunderstandings and findings from the previous studies formed a backdrop for reflections. Each study in the research project has added to the progression of the doctoral dissertation and the overall findings thereof. Could other methods of analysis have been chosen? Phenomenography was considered for Study IV, but a deductive approach was preferable, and thematic analysis was then perceived as appropriate. During the preparation phase for Study IV, the idea of applying a deductive approach was reconsidered in favour of an inductive approach, which could also be applied using a reflexive thematic analysis.

The overall trustworthiness (Graneheim et al., 2017) of the results in this doctoral dissertation have been ensured by the choice of relevant data collection methods based on the aim of each study. By adhering to each study's method of analysis as well as possible, clearly accounting for context, selection of participants and awareness of the analyst's preunderstanding, and exemplifying the different steps in the analysis process and in the generation of categories or themes, trustworthiness is also achieved (Elo et al., 2014;

Graneheim et al., 2017). In all the studies, a description of the method used, as well as both strengths and weaknesses, have been addressed to be as transparent as possible. All the steps in order to ensure trustworthiness can also assist in an assessment of transferability (Graneheim & Lundman, 2004) to another setting. As the findings in this doctoral dissertation have a regional connection, the transferability might be questioned. It could be assumed that some of the experiences and perceptions transcend regional borders; however, it is for the reader to contemplate whether the results can be relevant in other settings.

Ethical considerations

Throughout all the studies, the ethical principles of autonomy, nonmaleficence, beneficence and justice (Beauchamp & Childress, 2001; Beauchamp & Childress, 2019), have been reflected upon and considered. The data for Study I were retrieved from the invitational register consisting of information about the invitee's municipality of residency, birth data in order to establish age, and participation or non-participation in mammographic screening the year of invitation, and was treated with respect. This was due to the understanding of the trust placed in different authorities by the public when agreeing to share their personal data. Without this possibility to register personal information, much of the research and understanding of the past to be prepared for the future would be difficult to perform. As health research aims to, amongst other goals, improve health by producing knowledge (World Health Organization, 2012), nonmaleficence can be considered to be respected.

The impact the topic of mammographic screening might have on the informants was taken into consideration. For Studies II and III, the informants were women who did participate or had decided not to participate in mammographic screening. The reasons behind these decisions could range from the practical, such as financial hardships or fitting the appointment in the everyday life schedule, to personal beliefs, fears and degrees of more or less traumatic experiences. This was important to be sensitive about during the interviews so as not to make the informant feel uncomfortable or judged, especially for the informants who had decided not to participate. By emphasizing that there is no right or wrong when deciding on participation, which is respecting the autonomy of the woman, and that everyone has their specific reasoning, the interviewer strived for the informant to feel an atmosphere of acknowledgment of their specific situation, corresponding to the principles of nonmaleficence.

The data collection methods differed between Studies II and III. In Study II, focus groups were the chosen method, and the women all participated in mammographic screening. The sampling was a 'snowball', and many of the women worked at the same workplace and had similar educational

backgrounds and engaged in similar work. This homogeneity was taken into consideration, as workplace hierarchy can be pronounced and might have a dampening effect on the feeling of being able to speak 'from the heart'. It can also affect the willingness to speak and make one's voice heard. An awareness of these potential threats was kept in mind by the moderator during the discussions.

In both Study II and Study III, the sampling result was that not every woman in the county received an invitation to participate in the research study; hence not all were able to express their experiences and perceptions about mammographic screening. This could be perceived as not adhering to the principle of justice. However, just conduct was adhered to as well as possible by mailing out reminders about the opportunity to participate in the study to the women randomly selected in Study III. In Study II, the different means of trying to recruit participants to the group discussion may reflect the same striving for justice. In Study III, individual interviews were conducted, and many of the interviews took place in the informant's own home (according to the informant's choice), which allowed the informant to be interviewed in a more private and potentially more safe and comfortable environment. As the choice of where and when to be interviewed was up to the woman, autonomy as well as beneficence were respected.

In Study IV, individual interviews were also conducted, and here the ethical considerations mainly concerned the task to reach beyond the informant's professional political presentation and understand the perceptions of the 'private' individual. Awareness of this balancing act that the informants might experience between being the private person and the professional politician was reflected upon and concerned the principle of beneficence. For the informant (politician), the 'sitting in two chairs' might involve feelings of both risks or costs, which were weighed against the benefits of participation. In addition, the topic of mammographic screening may evoke feelings regardless of whether a person has a profession that involves answering questions of different natures and levels of sensitivity from both the public and peers. This was kept in mind in all interviews, as mammographic screening is often linked to cancer.

Future research

This doctoral dissertation addresses the importance of access to health care and many of the social determinants of health, such as health care as an organization, socio-economic conditions and geographic location, which influence participation in mammographic screening. However, there are groups of women who have not been heard. One group comprises women who live in the region but have migrated from other countries with different cultures and different health systems than Sweden. What are their experiences and perceptions of mammographic screening, as well as their reasons to participate or refrain? Another group that is even harder to reach is the women who are homeless. How do they reflect on access to and participation in these health services, if they do at all?

To further investigate perceptions held by politicians and other relevant actors within the health care system regarding equity in health care would also be interesting to investigate. This can be addressed from different perspectives, for instance in relation to steering documents and policies taken in the region to counteract inequity in health care. Finally, how do the regions in Sweden actively work with access to mammographic screening, do they differ, and if so, how and why.

Conclusions and practical implications

This doctoral dissertation provides a regional perspective on mammographic screening, from different angles, and concludes:

- Municipality of residency (a proxy for distance to the mammographic facility) may affect participation in mammographic screening.
- With older age, there is a tendency that participation is higher in comparison with the youngest age group (40–44 years).
- Structural conditions such as transportation, possibilities to take time off from work and knowledge about how to navigate the health system have an impact on the decision of whether to participate in mammographic screening.
- Personal encounters between the women and the personnel are important in the decision of whether to participate. The need to be heard, listened to and acknowledged as an individual is of great importance.
- To have participated once or several times is not a guarantee for continuous participation.
- Information distribution is perceived as a good strategy to increase knowledge about mammographic screening and is essential to make a well-informed decision. This is valid for both politicians and the women invited to participate in mammographic screening.
- To counteract potential inequities in health care, different forms of resources are needed and an effort to actively work towards that goal. One resource that also may be a goal can, for instance, be an action and time plan targeting an attainable and measurable goal to increase the participation rate in different groups where a low participation rate has been identified.

By taking part in and reflecting on the findings in this doctoral dissertation, a deeper awareness of the complexity surrounding access to and participation in mammographic screening, as well as other health services offered, can be reached. Participation in mammographic screening can be enhanced and be more of participating than just attending by addressing the individual's need to be heard. This does not necessarily mean that the request for certain special arrangements can be met, but to be heard and acknowledged as an individual

in an otherwise standardized procedure is important. The strategy of giving information about mammographic screening can be strengthened with more strategies that facilitate dialogue between politicians and residents.

The implication for public health is as follows: with an increased awareness of (1) the importance of access, (2) the influence the social determinants of health have on decisions regarding health, and (3) how a higher degree of participation can take place, even through a seemingly quick procedure such as mammographic screening, may increase trust in the health care system, as well as, willingness to continue to support a welfare system with universal coverage.

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