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Tackling the Silent Epidemic of Breast Cancer in Vietnam

A qualitative study examining barriers to early diagnosis

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Abstract

The increasing number of women being diagnosed with advanced stages of breast cancer in low- and middle-income countries is demanding an improvement in early detection strategies. This thesis examines the barriers to early diagnosis in Hanoi, Vietnam by analysing patients' paths from symptom recognition to initiation of treatment. Semi-structured qualitative interviews with 20 breast cancer patients are used to acquire individual perspectives and experiences of access, diagnostic and treatment delays and barriers creating these delays. A socio-ecological lens is used to analyse the barriers in relation to different levels of influence. In addition, two key-informant interviews are used to provide information about barriers at the policy level. The results indicate that a number of barriers exist, several of them cross-cutting across different levels of influence, potentially creating access and diagnostic delay. Low awareness among patients and health practitioners; stigma and misconceptions about breast cancer; financial as well as logistical barriers are identified as the main barriers to early diagnosis.

Key words: Barriers to early diagnosis, breast cancer, Vietnam, healthcare utilisation

Word count: 14,938

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Abbreviations

CCP	Cancer control plan
DALY(s)	Disability adjusted life-year(s)
HCMC	Ho Chi Minh City
HIC(s)	High income countries(s)
IARC	International Agency for Research on Cancer
LMIC(s)	Low and middle income countrie(s)
MoH	Ministry of Health
NCD(s)	Non-communicable disease(s)
NCH	National Cancer Hospital
NGO	Non-governmental organisation
OOP	Out-of-pocket
SDG(s)	Sustainable development goal(s)
SEA	Southeast Asia
QALY(s)	Quality-adjusted life year(s)
WHO	World Health Organisation

1. Introduction

Non-communicable diseases (NCDs), such as cancer, are great barriers for development in a country and limit the possibilities for poverty reduction, economic stability, human security and health equity (Beaglehole & Bonita, 2011). Therefore, to be able to achieve the Global Action Plan for Prevention and Control of NCDs as well as the United Nations Sustainable Development Goals (SDGs), appropriate strategies for reducing the burden of cancer should be prioritised in all countries (WHO, 2017a). The WHO states that low- and middle-income countries (LMICs) face major challenges in each of the following four areas of cancer control: cancer prevention, early detection, diagnosis, treatment and palliation (ibid.).

Similar to other NCDs, breast cancer is primarily associated with high-income countries (HICs), despite the fact that 53% of new breast cancer cases around the world occurred in LMICs in 2012 (Ferlay et al. 2015). The existing knowledge on breast cancer has mainly been based on research conducted in HICs, which limits the knowledge about effective prevention, diagnostic and curative strategies in LMICs. As preconditions such as healthcare quality, financing and health-seeking behaviour vary between high and low income settings, LMICs face challenges in tackling breast cancer that are substantially different than those faced by HICs. Research indicates that breast cancer incidence in LMICs will continue to rise, thus increasing the demand for extended knowledge about breast cancer prevention, detection and treatment in a greater variety of countries and populations (Trieu et al. 2015).

An essential aspect of decreasing the high mortality rate of cancer diseases is to implement early detection strategies, which increases the possibility of successful treatments (WHO, 2017a). Two fundamental elements of early detection of cancer are i) screening in a target population independent upon symptom identification and ii) early diagnosis in terms of “early identification of cancer in patients who have symptoms of the disease” (ibid.). It is, however, often difficult for LMICs to implement screening programs due to insufficient provision of financial and human resources, as well as the lack of knowledge about the cost-effectiveness of a nationwide screening policy (Corbex et al. 2012; Trieu et al. 2015). Thus, a less resource demanding and complex tool for reducing the cancer incidence rate and improving early detection strategies is improvements in early diagnosis capacity (Sankaranarayanan & Boffetta, 2014; WHO, 2017a). According to the WHO, the following three steps should be considered to improve early diagnosis of cancer (WHO, 2017a):

1. *Awareness of cancer symptoms and access to healthcare*
2. *Clinical evaluation, diagnosis and staging*
3. *Access to treatment*

Similar to many other LMICs, Vietnam is currently facing a double burden of disease as the prevalence of communicable diseases remain relatively high, while the incidence of NCDs, such as cancer, keeps increasing. Despite the increasing burden of cancer diseases, Vietnam has still not implemented a detailed national cancer control program, as recommended by the WHO (WHO, 2017a). Breast cancer is currently the most common cancer among women in Vietnam and the age-standardised incidence rate¹ has increased from 13.8 per 100,000 women in 2000 to 29.9 per 100,000 women in 2010 (Jenkins et al. 2018: 1). It is estimated that there were 11,060 new breast cancer cases in Vietnam in 2012 and a majority of these cases were diagnosed at an advanced stage (III, IV), and below age 50 (Trieu et al. 2015: 241). Although Vietnam has a relatively low incidence level, compared to other LMICs, the proportion of cases diagnosed at a later stage is substantially greater. This limits the possibilities for successful treatment and survival, which could explain the high mortality rate (Trieu et al. 2015).

Despite the increased awareness of the importance of early diagnosis, existing research on breast cancer in LMICs still focuses primarily on improvements in treatment capacity rather than on the preceding process of awareness and diagnosis (Demment et al. 2015). Studies suggest that in order to prevent late-stage diagnosis in Vietnam and other LMICs, research on barriers related to different aspects of early diagnosis need to be conducted before appropriate strategies can be implemented (Anderson, 2010; Jenkins et al. 2018; Sankaranarayanan & Boffetta, 2010).

Number of new cases, considering differences in age structure of the population (Ahmad et al. 2001).

1.1 Research aim

In order to identify appropriate strategies for reducing delay in diagnosis of breast cancer in Vietnam, this study aims to examine different barriers for early diagnosis and treatment. Analysing the healthcare-seeking behaviour of breast cancer patients and their perspectives concerning the path from symptom recognition to initiation of treatment, will help unfold the barriers to ensuring an early diagnosis. A socio-ecological lens, which takes into account both individual and structural factors will be used to examine barriers at different levels and discuss appropriate strategies to tackle these barriers. The data draws on interviews conducted at the national cancer hospital (NCH) in Hanoi during February-March 2018. In addition to qualitative interviews, a literature review of existing research concerning barriers to early diagnosis in LMICs will be conducted to enable comparisons and analysis.

1.2 Research questions

- 1. Which barriers to early diagnosis can be identified in the path from symptom recognition to initiation of treatment, according to the perspectives of breast cancer patients?*
- 2. How can these barriers be tackled, according to existing research?*

1.3 Disposition of thesis

The first section of this thesis will provide a contextual insight regarding the health status of the population and healthcare system in Vietnam. The section will further include an overview of healthcare expenditure, the structure of the healthcare system and health financing schemes. To be able to explain barriers to accessing cancer care, this section will also include information about cancer services in Vietnam.

The second section will explain the applied methods, sampling and analysis strategies, as well as provide a theoretical grounding. Although the socio-ecological model constitutes the central part of the theoretical framework of this thesis, other theoretical concepts will be adopted to acquire a deeper understanding of healthcare utilisation. The section will then

further include a part regarding existing research surrounding barriers to early diagnosis and treatment of breast cancer.

The final section of the thesis will present findings from the interviews, applied to theories and in the light of previous research. The analysis will be structured according to the levels of the socio-ecological model and include a part about strategies which could be used to tackle the identified barriers. Following the analysis, a concluding discussion will be provided with a presentation of main findings, the author's personal reflections and implication of future research.

2. Contextual insight

2.1 Health status

The *Đổi Mới* economic transformation initiated in 1986 transformed Vietnam's financial system from a planned Marxist economy to a market economy, which has contributed to substantial health indicator improvements during the past 30 years (World Bank, 2017). The GDP per capita has ascended from \$431.9 thousand in 1990 to \$1,735 million in 2015 (constant 2010 US\$), which has advanced the expenditure of infrastructure and access to primary services (World Bank, 2018). The following table provides an overview of the development of demographic and health indicators in Vietnam during the last two decades.

	2000	2005	2010	2015
Life expectancy at birth, female (years)	78,1	79,2	79,9	80,7
Life expectancy at birth, male (years)	68,4	69,3	70,1	71,2
Mortality rate, infant (per 1,000 live births)	23,6	20,2	18,6	17,6
Mortality rate, under-5 (per 1,000 live births)	30,0	25,3	23,3	22,0
Prevalence of underweight, weight for age (% of children under 5)	26,7	22,7	12,0	..
Maternal mortality ratio (modelled estimate, per 100,000 live births)	81,0	61,0	58,0	54,0
Fertility rate, total (births per woman)	2,0	1,9	1,9	2,0
Mortality rate, neonatal (per 1,000 live births)	15,2	13,0	12,3	11,7

Source: World Bank (2018).

Several health indicators have improved remarkably in Vietnam during the last two decades. Economic prosperity enabled improvements in healthcare services, which developed the

conditions for safe childbirth. The infant mortality rate decreased from 23,6 in 2000, to 17,6 in 2015 and the maternal mortality rate declined from 81,0 in 2000, to 54,0 in 2015. The life expectancy has continued to rise in Vietnam and is currently the highest among the LMIC in SEA (World Bank, 2018).

Although the health status of the Vietnamese population has generally improved during the past 30 years, a number of health challenges remain. Despite high life expectancy, the burden of disease measured by disability adjusted life-years (DALYs) is, similar to other LMICs, high in Vietnam. This indicates that the probability of premature deaths and/or years lost due to illness is high (WHO, 2017b). Furthermore, Vietnam has undergone a demographic transition, which has increased the share of NCDs and put a strain on the healthcare system (Minh et al. 2013). Simultaneously, infectious diseases such as dengue fever, HIV/AIDS and malaria remains a heavy burden.

Although the malnutrition rate among children in Vietnam has decreased during the last decades, it is still high compared to other countries in Asia (UNICEF, 2001). In addition, large disparities in health status between the population in rural and urban areas and among socioeconomic groups can be observed and studies found that the risk of child malnutrition, NCDs and risk factors, such as smoking, was higher among lower socioeconomic groups and minorities (Kien et al. 2016; Kien et al. 2017a; Kien et al. 2017b).

2.2 Healthcare system and expenditure

The healthcare system in Vietnam is structured into three fundamental levels, with the Ministry of Health (MoH) at the tertiary level. The MoH is responsible for setting the health policy agenda and specific programmes aiming to improve the health of the population (WHO, 2011). The 63 provincial health bureaus in Vietnam are subordinate to the MoH and are governed by the People's Committees. The primary level in the healthcare system consists of district health centres, commune health stations and village health workers (ibid.).

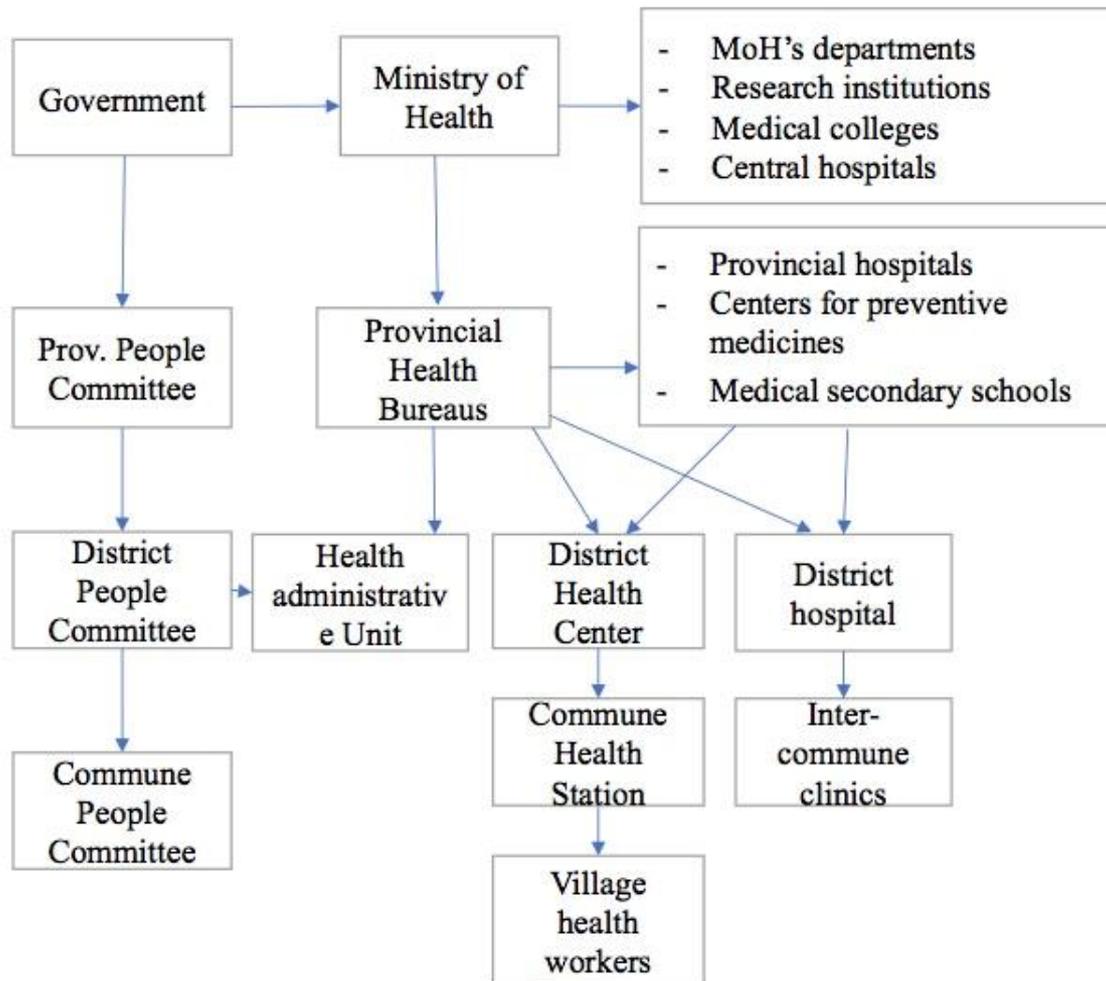


Figure 1: Structure of the healthcare system in Vietnam (researcher’s own construct based on WHO, 2011)

2.3 Health financing

As in many other socialist countries, the health expenditure in Vietnam was previously primarily financed by government revenue. Economic instability caused by the Vietnam war (1955-1975) strained the healthcare system, and a number of reforms aiming to improve the insufficient health services were introduced by the government. Private healthcare providers were included in the healthcare system, and health insurance was implemented, which increased the out-of-pocket² (OOP) expenditure on healthcare (WHO, 2011). The health financing in Vietnam has since then been based on, as in many other LMICs, on several sources: government

² Non-reimbursable healthcare expenses which are paid directly to the provider (WHO, 2011).

funding, OOP payments, social health insurance, external aid and private health insurance (WHO, 2011).

The government health expenditure is mainly allocated through direct financial support to health providers. In addition, a significant contribution of the health expenditure is used to subsidise the healthcare expenses of vulnerable populations, through national insurance schemes (Minh et al. 2013; WHO, 2011). The main national insurance scheme is the social health insurance, which subsidises the health insurance for formal sector employees, pensioners, the poor, children and partially subsidising the health insurance for the near-poor and students (World Bank, 2014).

Although the health expenditure in Vietnam is relatively high, compared to other LMICs in SEA, the healthcare system still faces a number of challenges. Firstly, studies evaluating the primary care services in Vietnam indicate that it lacks in terms of quality, which could be the result of insufficient funds invested in primary care (Minh et al. 2013; World Bank, 2013). Secondly, despite substantial investments in human resources and healthcare personnel, there is still a shortage of human resources for healthcare. In addition, the healthcare personnel often lack the required expertise, which limits the possibility to obtain efficient and high-quality healthcare services (Minh et al. 2013; World Bank, 2013). This is particularly a challenge at commune level and in rural areas, due to fewer incentives for the healthcare professionals. Although the majority of the Vietnamese population live in rural areas of the country (65%), 59 % of the medical doctors in the country are employed in urban areas (JAHR, 2015: 247).

In 2012, the Vietnamese government committed to reaching the goal of universal healthcare coverage, by increasing the social insurance coverage to 70 % by 2015 and 80 % by 2020 (World Bank, 2014: 2). Although the enrolment rate increased during the last decade, it is still considerably low. The compulsory social health insurance is still only partially covering the health insurance for the near-poor and other groups, which limits the possibilities for a high enrolment rate (World Bank, 2014). The OOP expenditure has historically played a large part in the healthcare expenditure in Vietnam and is still on the rise. Although efforts have been made to decrease the prevailing OOP rate, it has ascended from 16 US \$ per capita in 2006, to 51 \$ per capita in 2015 (WHO, 2017c). Figure 2 provides an overview of the health financing schemes in Vietnam during the years 2006-2015.

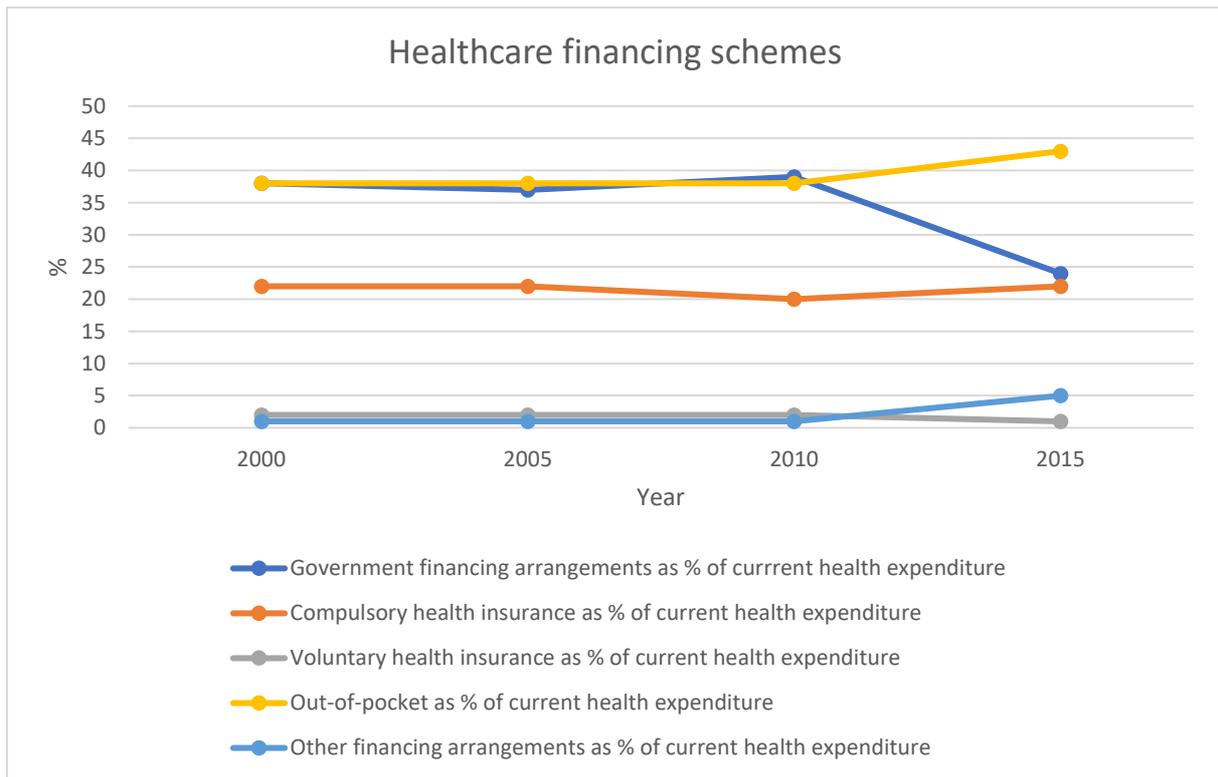


Figure 2: Healthcare financing schemes Vietnam (WHO, 2017c).

2.4 Cancer services

Data indicates that the insurance coverage rate for cancer patients varies geographically and between socioeconomic groups and does not fully cover the healthcare expenses for diagnostic and treatment services (Jenkins, 2018). The national health insurance reimburses cancer patients with 80% of examination and treatment expenses and the rest of the costs are paid OOP (Jenkins, 2018: 7). Depending on treatment type and pharmaceuticals used, the OOP expenditure highly varies (ibid.).

The cancer care services in Vietnam are regulated in line with the guidelines developed by the MoH. Most of the diagnostic services are offered at hospital's oncology units and specialist oncologist hospitals. There are currently six specialist oncology hospitals across the country and 43 oncology units in other hospitals (Jenkins, 2018: 6). The cancer treatment services are highly concentrated to the larger cities and there are two national specialist treatment hospitals: K hospital in Hanoi and HCM cancer hospital in Ho Chi Minh city (HCMC) (ibid.).

Although national screening programs have not yet been implemented in Vietnam, several pilot screening programs have been employed. A recent report indicates that over 120,000 women have participated nationally in the screening programs from the year 2008 to 2013 (MoH Vietnam, 2014: 22), covering approximately 10% of eligible women (Harper, 2011: 6). These screening programs are, however, not covered by the national insurance and are difficult to implement on a wider scale as data on the implementation process is deficient, making results difficult to monitor and evaluate (Jenkins, 2018). Furthermore, the pilot programs have been primarily focusing on targeting the population in large cities such as Hanoi and HCMC and have therefore not covered the rural population (*ibid.*).

3. Theoretical framework

3.1 Theories of healthcare utilisation

To be able to explain the late diagnosis of breast cancer patients in Hanoi, an analysis of both healthcare-seeking behaviour and other factors influencing the path from the discovery of symptoms to initiation of treatment is needed. A good starting-point for unfolding barriers related to the healthcare system and access to efficient, good quality diagnosis and treatment is theories that explain healthcare utilisation.

Healthcare utilisation is often explained within a mixed demand-supply framework. The access to health services is dependent upon supply-side factors, in terms of availability of efficient and good quality healthcare. On the demand side, healthcare utilisation is determined by factors impacting the patient's decision to seek care (O'donnell, 2007; Ensor and Cooper, 2004). Barriers for healthcare utilisation can occur on both sides and it is therefore important to consider each of them when analysing the access to health services in a population (O'donnell, 2007). The following section will provide an overview of the primary explaining variables, impacting the access to healthcare in relation to supply and demand sides.

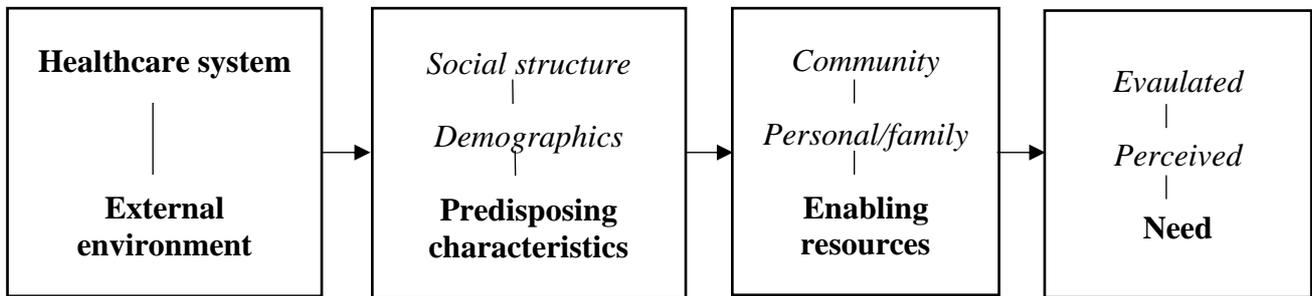
Most studies on healthcare utilisation in low- and middle-income settings focus on the supply side and the access to essential health services (O'donnell, 2007). As the health systems in LMIC are often insufficient, due to instability or a lack of resources, health services might not be offered to the population or could be lacking in terms of quality and efficiency (*ibid.*).

On the demand side, various health behavioural theories aim to explain an individual's decision for seeking healthcare. The most widely used are the Health Belief Model, Stages of Change and the Theory of Planned Behaviour. These theories focus on individuals' perceptions of the illness and the treatment and the community's attitudes towards it, as well as perceived behaviour and control (Gipson and King, 2012). Although these models provide important frameworks for explaining individual health behaviour, they do not acknowledge the influence of the healthcare system, health policy and other structural factors and will therefore not be used in the analysis.

A large body of evidence indicates that one of the main determinants for seeking healthcare is education (Ensor and Cooper, 2004; O'donnell, 2017). This is explained by an improved health literacy, which influences care seeking behaviour (Ensor and Cooper, 2004). Other factors affecting the decision to seek healthcare are financial barriers such as transportation and healthcare costs, as well as norms and stigma associated with the illness at a community or household level (ibid.).

Scholars such as Andersen (2014) and McLeroy (1988) stress the importance of considering determinants at different levels as healthcare utilisation is not only determined by individual factors. Other important levels of influence include context, in terms of "circumstances and environment of healthcare access" which often display as beliefs, practices and values in a setting (Andersen, 2014). Concepts from the Healthcare Utilisation Model (Andersen, 1995) will be used in this thesis to integrate the different levels of influence regarding the healthcare utilisation of breast cancer patients. The following figure provides an illustration of the concepts affecting healthcare utilisation, which will be used to analyse the healthcare-seeking behaviour of the participants.

Figure 3: Healthcare Utilisation Model (researcher’s own construct based on Andersen, 1995)



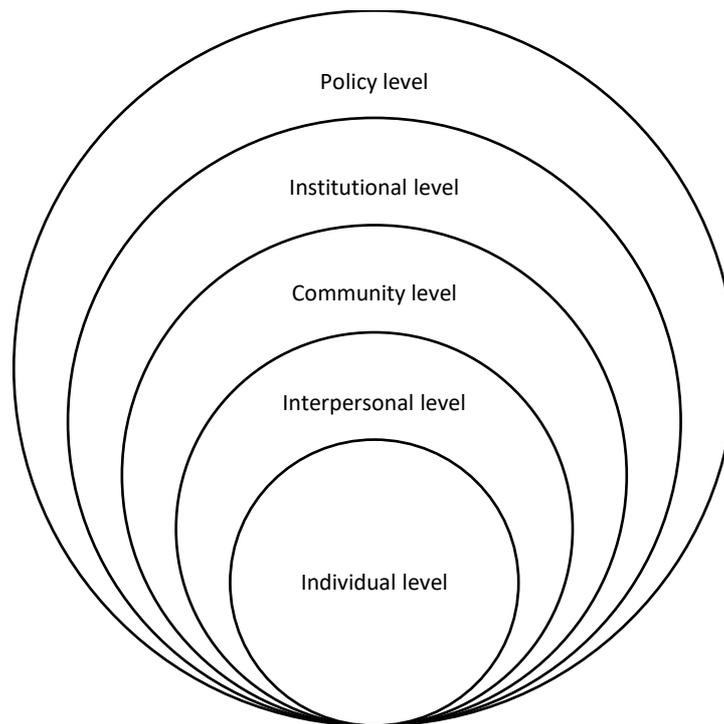
Although the model provides an extensive analysis of determinants of health service usage, it includes several aspects which will not be covered in this thesis. Individual characteristics in the most recent Healthcare Utilisation Model include genetics, which is beyond the scope of this thesis. Outcomes such as consumer satisfaction and quality-adjusted life years³ (QALY) will further not be included, due to the irrelevance for this study. This study examines the path from symptom recognition to initiation of treatment but does not aim to analyse outcomes of the treatment.

3.2 Socio-ecological model

In order to explain the barriers to early diagnosis of breast cancer, and the mechanisms for healthcare-seeking behaviour, this thesis will analyse barriers through a socio-ecological lens. The socio-ecological framework, following the model by McLeroy (1988) has previously been used to explain behaviours in relation to cervical cancer screening (Lee and Carvallo, 2014) and barriers to early detection of breast cancer in Uganda (Llaboya et al. 2018). It emphasises the interaction of different factors influencing health and health behaviour. The levels of influence include: individual, interpersonal, community, institutional and policy level (CDC, 2015).

³ A measure of disease burden, considering both quality and quantity of life years (Whitehead and Ali, 2010).

Figure 4: *Socio-ecological model* (researchers own construct based on CDC, 2015)



Previous studies of early diagnosis of breast cancer in LMICs found that a combination of these levels of influence needs to be considered to explain the barriers to early diagnosis of breast cancer. The WHO states that the four main groups of barriers to early diagnosis of cancer are: awareness, sociocultural⁴ barriers, logistical barriers and financial barriers (WHO, 2017), hence, these barriers will be examined at different levels of influence.

Operationalisation of theory

The study will use a multilevel-approach to analyse these barriers and categorise them in accordance with the different levels in the socio-ecological framework. This approach will enable an assessment of barriers and the impacting mechanisms at different levels. However, as the interview questions are semi-structured, information which does not fit within this framework might appear. The socio-ecological model thus serves as a tool for analysis but will be altered and applied on field narratives.

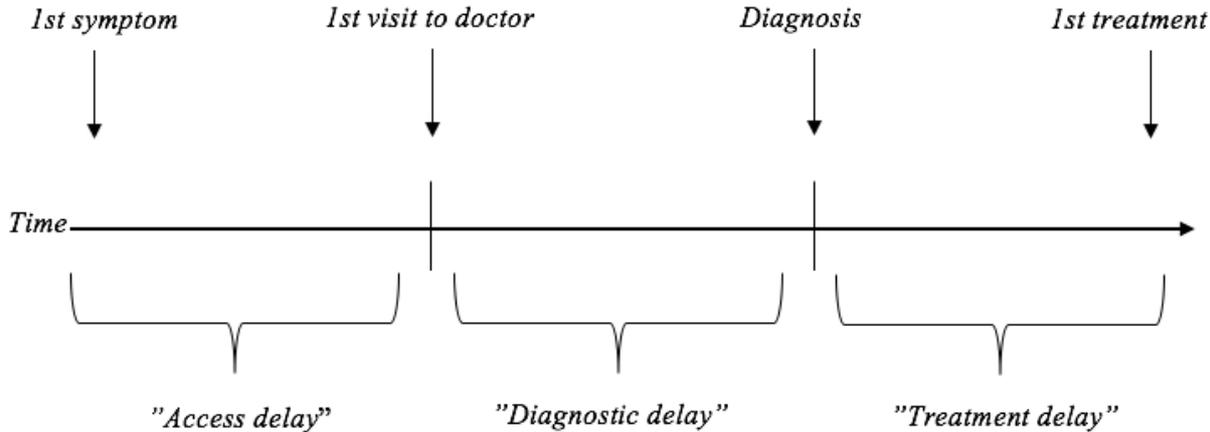
⁴ Social and cultural factors (WHO, 2017a).

Barriers examined at the individual level concern patients’ own attitudes towards healthcare services and their experience of the procedure from symptom recognition to initiation of treatment. Barriers at interpersonal level concern social networks, including family, friends and neighbours, while community-level factors include attitudes and influences from larger groups in the community, for example, churches and voluntary associations. Barriers at institutional level primarily concern the healthcare system and provision of health services, and policy level pertain to the current policy agenda.

3.3 Delays within the healthcare system

The barriers will further be used to explain different delays in the pathway from first symptoms to initiation of treatment. The following figure illustrates the different delays within the healthcare system.

Figure 5: Delays within the healthcare system (researchers own construct based on WHO (2017a))



Barriers can occur during the whole pathway, creating different types of delays. Generally, the pathway is segmented into three main components; access delay, diagnostic delay and treatment delay (WHO, 2017a). Recommended timeframes for the different intervals vary in research, however, a great number of studies suggest a three-month limit for the patient interval from symptom recognition to contact with a health practitioner. Longer periods than three months

cause access delay (Burgess et al. 1998; Granek et al. 2012; Olesen et al. 2009). The diagnostic delay occurs when there is a prolonged time-interval between the first visit to a health practitioner and a diagnosis, which is usually a period of more than one month (WHO, n.d.). The treatment delay is defined as the period from diagnosis to the first treatment and it is recommended not to exceed one month (ibid.). These time-intervals will, however, not be measured in this thesis, but will serve as concepts to discuss barriers in relation to different delays.

4. Methodology

4.1 Research approach

The study employs a qualitative approach in order to explore the perspectives of breast cancer patients on possible barriers to early diagnosis. The use of a qualitative methods approach enables the collection of data from individual experiences of health services and delay in diagnosis and treatment, rather than quantification of information (Bryman, 2012: 380). The study is designed as a single-case study, employing a ‘holistic approach’ as it focuses on one unit of analysis (Yin, 2009: 50). Although both patients and key-informants are interviewed, the unit of interest is solely breast cancer patients path from symptom recognition to initiation of treatment and barriers within the pathway. A case study was chosen as a research design, as the aim of the study is concerned with “the complexity and particular nature of the case in question” (Bryman, 2012: 66). Furthermore, the case study can be considered as an exemplifying case, as it “exemplifies a broader category of which it is a member” (Bryman, 2012: 60).

Several aspects of qualitative research methods are often criticised, including the lack of possibility for generalisation and establishing correlations between variables (Mikkelsen, 2005: 92). Although these aspects are important to consider when choosing methodology, the aim of this thesis is primarily to study barriers to early diagnosis and treatment in the Vietnamese context, deriving from patient experience and healthcare-seeking behaviour; which is why a qualitative approach is suitable. Rather than using a natural scientific model, qualitative research aims to analyse the social world through perceived views of the respondents (Bryman, 2012: 280). Although the results focus only on a small number of patients and thus cannot be

generalised, a qualitative approach enables the derivation of rich information about a certain group of respondents, thereby fulfilling the aim of this study.

4.2 Sampling

The study was conducted at the Department of International Collaboration and Research at the National Cancer Hospital (NCH) in Hanoi. Research was conducted in Hanoi due to the high incidence of breast cancer. Although limited data exist on cancer incidence rate in Vietnam, data indicates that the rate is almost twice as high in Hanoi, when compared to Vietnam's second largest city, HCMC (Trieu et al. 2015: 242).

As qualitative studies are dependent upon a richness of information, rather than a great number of informants (Bryman, 2012: 425; Cresswell, 2013: 189), the number of patients were not decided beforehand. The sample size was considered to be sufficient and theoretically saturated when no new information emerged from additional interviews. In total, 20 patients were interviewed, two with stage I, twelve with stage II and six with stage III breast cancer. In addition, four pilot interviews were used to ensure that the questions were understood correctly and appropriate to the context of the study. The interview questions were subsequently altered according to the pilot interviews.

The interviews were conducted during a 3-week period, simultaneously after doctor appointments at the NCH. Purposive sampling was used with solely one criterion, that the participant was a woman diagnosed with breast cancer. Although probability sampling was not employed, the study still aimed to target a broad group of patients with a variety of perspectives. As only two specialist cancer hospitals exist in Vietnam, a variety of patients from both urban and rural areas in Vietnam were reached. Therefore, purposive sampling was considered to be the most appropriate sampling method for this study. The importance of sampling a variety of patients for this study will further be discussed in the introduction of the analysis section. The sample of key-informants was decided based on the intention to include perspectives from several professionals within cancer care.

4.2.1 Secondary data

To be able to establish an understanding of the topic in Vietnam and in other low- and middle-income settings, a literature review of barriers to early diagnosis was conducted. The articles included in the literature review were searched through the medical database PubMed. Initial key words used in the search were: “*early diagnosis*” OR “*early detection*” AND “*barriers*” AND “*breast cancer*”. Only studies concerning barriers to early diagnosis of breast cancer in LMICs were included. Additional articles were obtained through the reference list of relevant articles. Furthermore, articles were used in the analysis to enable triangulation of findings. The articles were acquired through Scopus and PubMed and were chosen based on relevancy and publication year. The policy level analysis was, in addition to key-informant interviews also based on reports found through Google Scholar and documents acquired from the NCH.

4.3 Interviews

The primary source of information for this thesis was individual semi-structured interviews with breast cancer patients (appendix C). Semi-structured interviews are beneficial to use when the aim is to gain detailed answers and not limit the interviews by pre-decided answers (Bryman, 2012: 471). A semi-structure provides a fundamental framework to the interview, but does not hinder the researcher from asking follow-up questions and departing slightly from the questions in the interview guide (ibid.). Individual interviews were chosen instead of focus group interviews due to the sensitivity of the topic and to enable more in-depth individual discussions with the patients.

As few patients spoke English fluently, a research assistant at the NCH assisted with translation during the interviews. Having a translator might impact the results as the translated parts of the interviews are only a summary of what is being said (Mikkelsen, 2005: 97). However, using a translator can also be beneficial if the person is aware of cultural and contextual circumstances which are not evident to the researcher (ibid.). As the research assistant has facilitated similar studies at the NCH and participated in the discussions related to the study, she was aware of the importance of detailed information. In addition to individual interviews with patients, two key informant interviews were conducted with oncologists and researchers at the cancer hospital. These interviews provided information about policy implications, cancer strategies and key-informants perspectives regarding policy barriers.

4.4 Data analysis

The data was analysed using Creswell's six steps-approach: "organising and preparing data; reading through all the data; coding of data; identification of major themes and descriptions; determining the representation of data; and interpretation of findings." (Creswell, 2014: 195-196). To establish an initial coding scheme and understanding of the qualitative data, the transcript of the interviews was read several times. The data was transcribed manually, short after interviews, which enabled an awareness of the finding early in the process (Creswell, 2014: 195-6). This approach also allowed the method of including solely the number of patients required for saturated data. Following the transcription, themes were coded and sorted using NVivo as well as categorised following the different levels of barriers of the socio-ecological model. In addition, the concepts of healthcare utilisation were used to explain barriers in the healthcare system and the healthcare-seeking behaviour of breast cancer patients.

4.5 Level of trustworthiness

In contrast to quantitative research, there are no universal measures of quality for qualitative research. The concepts of reliability and validity have been debated when applied to qualitative studies and alternative criteria has been proposed (Bryman, 2012: 389). Hence, this study has instead adopted the four criteria of trustworthiness (credibility, transferability, dependability and confirmability), as suggested by Guba and Lincoln (1994).

To ensure *credibility*, in terms of a correct understanding of the narratives of the participants, this study has applied several methods. In addition to qualitative interviews with cancer patients, information from policy documents and interviews with key-informants were used to be able to analyse barriers at policy level and enable triangulation of results, which improves the level of credibility of a study (Guba and Lincoln, 1994). The results were further discussed with researchers at the hospital to be able to question assumptions and enable triangulation of perspectives.

The criteria of *transferability* can be difficult to ensure in qualitative research, as the data collection is often based upon a limited number of participants in a specific context (Bryman, 2012: 392). However, according to Guba and Lincoln (1994), transferability can be justified with detailed descriptions of the collected data, which can be used to investigate possible

applications of findings to other contexts. Although this study might not be transferable to other contexts, it aims to provide illustrative data, which then could be used to gain accumulative knowledge about barriers to early diagnosis of cancer.

The criteria of *dependability*, in terms of replicability and consistency of data, is partially attained in this study. Although replicability of the study might be difficult due to contextual circumstances, the thesis provides detailed descriptions of the research process. In addition, to ensure that the questions were suitable for the cancer type, the questions used originated from the quantitative questionnaire developed by the WHO and were altered in accordance with the context-specific aspects. This enables a consistent data collection method, which could be tried out in other contexts. Although the last criteria of *confirmability*, in terms of objectivity, is difficult to completely ensure when conducting qualitative research (Bryman, 2012:392), efforts were made to disallow personal values from affecting the research process. A field diary was used for self-reflection and to be able to identify assumptions and potential biases.

4.6 Limitations of the study

This study has several limitations which should be acknowledged. As the study focuses on perceptions of a certain group of patients, interviews were conducted at only one hospital in Vietnam, which is why it is not possible to generalise the results. Furthermore, this study primarily focuses on the individual, interpersonal and the institutional level of influence and a deeper investigation regarding policy implications could have been beneficial. However, as only two key-informant were interviewed and there was limited access to policy documents, a more extensive analysis into this matter was not possible. The study would further benefit from a mixed methods approach, in order to measure the different types of delays in relation to the identified barriers. However, as the focus of this study was individual perspectives of patients, a qualitative approach was preferable.

4.7 Ethical considerations

Interviewing patients is especially ethically sensitive as the participants might experience psychological distress when discussing the illness and the circumstances for not seeking healthcare. Therefore, this study has considered various ethical aspects in order to ensure that it is ethically appropriate. In addition to an ethical clearance obtained by the NCH in Vietnam,

the study has also been conducted with consideration of the four primary ethical requirements of the Swedish Research Council (Vetenskapsrådet) for the Humanities and Social Sciences: information, consent, confidentiality and use requirement (Swedish Research Council, 1990). Due to the sensitivity of the topic, the study also assessed the WHO guidelines on conducting interviews with patients in low-income settings (WHO, 2013). To ensure that the participants were aware of the implications of the study and their role, a background of the study and its elements was introduced prior to the interview (appendix A). The participants were also informed that the study was voluntary and that they had the right to withdraw at any time during the interview if they experienced discomfort.

All participants were given a consent form to sign (Appendix B) and the consent of illiterate participants was recorded. The patients were also informed about the possibility to impact the circumstances, time and place for the interview. As the patients were introduced through researchers at the hospital, it was essential that the individual patients could not be identified through the data. The interviews were, therefore, translated by a research assistant at the hospital, who assigned specific identification numbers to each patient instead of name. The research assistant had assisted with similar studies and was aware of the importance of not pressuring the participants and ensuring confidentiality, due to the sensitivity of the study.

In regard to reciprocity, it can be problematic to buy gifts or pay the participants due to an upholding of financial and socio-economic differences between the interviewer and respondent (Scheyvens et al. 2003: 157). However, following the results of this study, an indirect contribution was given to the participants, in terms of a financial donation to an organisation working to raise cancer awareness in Vietnam (Bright Future Fund).

5. Existing research

Studies previously conducted on breast cancer in LMICs found that various factors could explain the delay in diagnosis and treatment. The following sections provide a review of the existing knowledge on barriers for early diagnosis of breast cancer in a variety of LMIC and continents. Although the results might be context-specific and therefore challenging to apply to different settings, they provide an overview of barriers that are important to consider and

examine in Hanoi. Following a review of barriers in a variety of context, previous research on barriers to early diagnosis and healthcare utilisation in Vietnam will be discussed.

5.1 Barriers for early diagnosis of breast cancer in LMICs

Low awareness

A high number of studies conducted in low income settings, indicate that low awareness is one of the leading barriers for early diagnosis of breast cancer (Akuoko et al. 2017; Al-naggar, 2011; Al-sakkat et al. 2016; Anderson et al. 2011; Kohler et al. 2017; Lim et al. 2015; Llaboya et al. 2018; Salako et al. 2017; Talib et al. 2016). Low awareness can be observed regarding both inadequate knowledge about the symptoms of breast cancer (Anderson et al. 2011; Kohler et al. 2017; Llaboya et al. 2018) and lack understanding of the treatment procedure, as well as general misconceptions about breast cancer (Andersen et al. 2011; Kohler et al. 2017). Furthermore, a study conducted in Malawi found that the general knowledge about cancer services and where to access clinical breast examination is lacking (Kohler et al. 2017). The low level of awareness in many low resource settings is one of the explanatory factors for a delay in the period between presentation of symptoms and primary care examination, which is crucial for the early diagnosis of breast cancer (Anderson et al. 2011).

Sociocultural barriers

Delay in primary care examination can also be explained by sociocultural factors, such as misconceptions about cancer diseases, which increases the demand for alternative care instead of traditional cancer treatments at the hospital (Anderson et al. 2011). Other studies on healthcare utilisation of breast cancer patients have also introduced stigma as an explanatory factor. Certain beliefs and traditions in a community can impact the way cancer diseases are perceived and has in several cases prevented women from seeing a health practitioner, despite presentation of symptoms (Akuoko et al. 2017; Dey et al. 2016; Herford, 2011; Meacham et al. 2016; Salako et al. 2017).

Structural barriers

Although individual factors explain individual healthcare-seeking behaviour and barriers related to the presentation of symptoms, several studies indicate that structural barriers are essential to consider when examining delay in diagnosis and treatment of breast cancer. The

healthcare systems are often insufficient in low-income settings, which limit the access to efficient, high-quality healthcare (Anderson et al. 2011). Several studies found that lacking knowledge is not only an explaining variable for the access delay, but also for diagnostic and treatment delay (Anderson et al. 2011; Talib et al. 2016; Lim et al. 2015). Late stage diagnosis could be explained by nurses and primary care physicians' insufficient knowledge about the symptoms of breast cancer, thus failing to pay attention to warning signs (Anderson, 2010). A study conducted in Malaysia found that one explaining factor for delay in diagnosis of breast cancer was missed diagnosis among health practitioners (Lim et al. 2015). The diagnostic delay is furthermore explained by a weak healthcare capacity and conflicting healthcare burdens in the country (Llaboya et al. 2018), as well as low quality of healthcare services (Lim et al. 2015).

Weak healthcare systems often have higher rates of OOP payments for healthcare, which is also identified as a barrier for healthcare utilisation of breast cancer patients in LMIC (Anderson et al. 2011). Studies on early diagnosis of breast cancer in India and Uganda found that access delay was often caused by financial constraints (Dey et al. 2016; Llaboya et al. 2018). In addition to financial barriers, logistical barriers in terms of transportation difficulties are identified in studies of early detection and diagnosis of breast cancer in several African countries (Kohler et al. 2017; Llaboya et al. 2018).

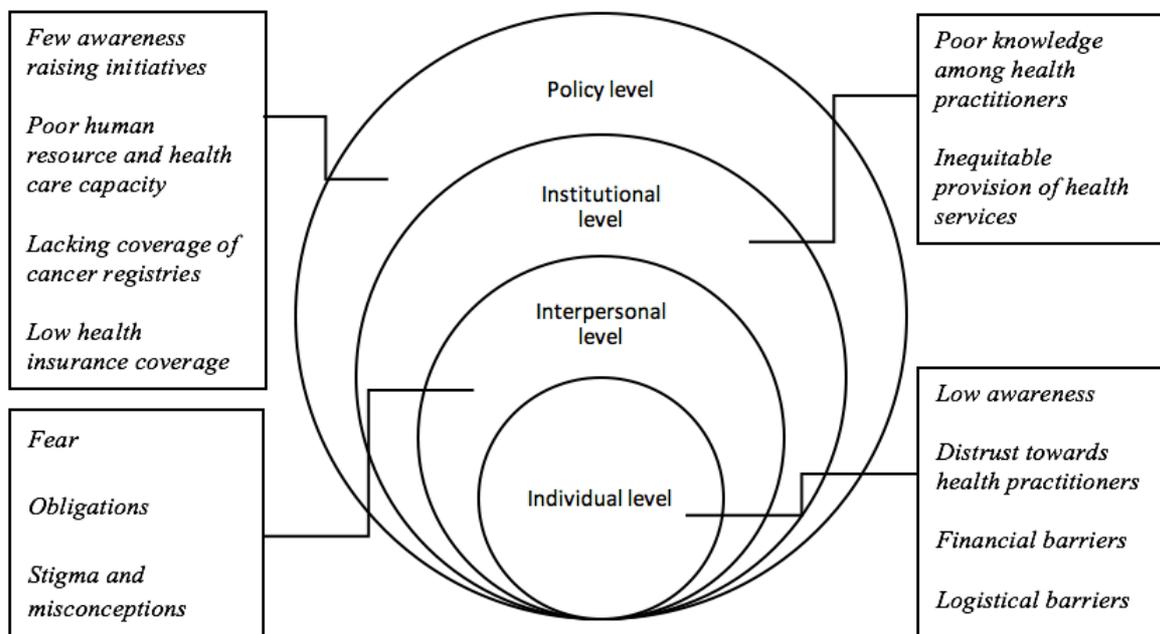
5.2 Early diagnosis of breast cancer in Vietnam

The existing knowledge on barriers to early diagnosis in Vietnam, as in other countries in SEA, is very scarce and limited, as studies on breast cancer focus more on explanations for the increasing incidence rate. Studies on healthcare utilisation in Vietnam indicate that there is a high level of OOP health expenditure and many households experience catastrophic health expenditure (Minh et al. 2012). This finding is especially interesting when studying financial barriers to early diagnosis of breast cancer, as high OOP health expenditure could be an explanation for access delay. In terms of supply-side barriers, studies indicate that the general cancer care capacity and specifically diagnostic services, are deficient in Vietnam (Jenkins et al. 2018). Trieu et al. (2015) have examined the rising incidence rate of breast cancer and the high number of patients being diagnosed at an advanced stage in Vietnam. Suggested explanations are poor awareness, lack of breast cancer screening programs and few general practitioners (Trieu et al. 2015). However, no qualitative studies have examined barriers to early diagnosis of breast cancer in Vietnam to date (Jenkins, 2018).

6. Analysis

The following section will present findings of the individual semi-structured interviews, structured according to the socio-ecological model (McLeroy et al. 1988). As McLeroy et al. (1998) emphasise, one level is interdependent from the others and, the individual level is affected by community and policy. However, to be able to illustrate the intersections of the barriers at different levels and improvements related to these, the structure of the analysis will focus on separate levels. During the content analysis, four major themes were identified at the individual level, three at the interpersonal level, two at the institutional level and four at the policy level. The interpersonal and community levels were combined as these barriers were intersected during the analysis and could, therefore, not be separated. Figure 6 illustrates the barriers identified at different levels of influence.

Figure 6: Barriers at different levels of influence (researchers own construct)



In order to explain the healthcare-seeking behaviour of the participants, the mechanisms of the barriers were analysed using individual and contextual factors. Predisposing factors, in terms of personal and societal beliefs were identified at individual, interpersonal and community level and integrated into the analysis of the barriers. Enabling resources were used to explain financial and logistical barriers at individual and policy level. The perceived need of patients is a crucial part of acquiring health services and is used as a concept to explain the awareness and knowledge about breast cancer and its symptoms. It is however important to also acknowledge evaluated need, in terms of health practitioner's knowledge about breast cancer and how it affects patients access to timely diagnosis and treatment. The concept of perceived and evaluated need has, therefore, been discussed at both individual and institutional level. As previous studies indicate that logistical barriers exist for women situated in distant areas, it was important to reach these patients as well. A majority of the respondents were situated in rural areas, which enabled an analysis of logistical and financial aspects of travelling to the hospital. To be able to establish an understanding of the respondents, figure 7 provides an overview of the characteristics of the participants.

Figure 7: Characteristics of participants

Characteristics of participants	Participants (N)
<i>Stage at diagnosis</i>	
I	2
II	12
III	6
IV	0
<i>Age group</i>	
<40	1
40-50	7
>50	12
<i>Type of community</i>	
Urban	2
Rural	18
<i>Education</i>	
Secondary school	16
University	4
<i>Payment of medical expenses</i>	
100 % PHI*	12
80-95 % PHI	4
80 % PRI**	1
40-50 % PHI	3

*Public health insurance

**Private health insurance

6.1 Individual level

Awareness

Personal beliefs such as awareness and knowledge about health issues and healthcare can be categorised as individual predisposing factors impacting the decision to seek healthcare and the health outcome (Andersen, 1996). Several themes identified at the individual level are particularly relevant when analysing barriers impacting access delay. One of the most essential aspects of accessing timely healthcare is recognition of symptoms (Ensor and Cooper, 2004). Health literacy, in terms of understanding, assessing and assimilating health information is, therefore, an important determinant of access delay (Levy and Janke, 2017). In line with previous research examining barriers for early diagnosis, low general awareness about breast cancer was identified during the interviews. Many respondents were not aware of the symptoms

of breast cancer prior to their own diagnosis. Several women stated that they found a lump in their chest but did not believe it could be breast cancer.

“I was shocked when I found out it was breast cancer. I did not know that a lump was a symptom before the doctor told me.”

Respondent 01 (2018-02-19)

The poor knowledge about symptoms of breast cancer could possibly be explained by the fact that 18 of the respondents were situated in rural areas where cancer awareness campaigns are not as common, and the access to health services is limited (Jenkins et al. 2018). A study examining healthcare-seeking behaviour in a rural area in Vietnam found that people tend to utilise private healthcare rather health services at public hospitals and communal health station, as well as practice self-treatment to a greater extent (Khe et al. 2002). As cancer departments are mainly located in urban areas, the rural population acquire health services not only at health centres and hospitals but also at traditional health practitioners. Several women mentioned that they contacted a traditional healer when discovering symptoms and two women initiated alternative treatment in their village.

“When I found the lump I went to a traditional doctor in the mountains as most people go there to get treatment. I got a leaf for treatment but it was not effective so then I went to the hospital.”

Respondent 10 (2018-02-27)

Although disbeliefs towards traditional healing options were mentioned, the patients explained the decision to see a traditional healer by the fact that it was common in the community. When the symptoms intensified, they decided to see a health practitioner at a hospital instead. One respondent waited three years before getting an examination at a hospital and when she got a diagnosis she had stage III breast cancer.

“I went to see a traditional doctor in my village in 2012. He gave me a healing leaf which would treat my pain. I then waited three years and did not know it was cancer. But it started to hurt more and more so I went to a hospital in 2015 and then I had stage three cancer.”

Respondent 04 (2018-02-23)

The level of knowledge about breast cancer can affect the time of diagnosis but also the treatment procedure. Although oncologists offer treatment advice, patients can influence the treatment type. A few women experienced that they had a comprehensive knowledge base about breast cancer and different treatment options, which impacted the choice of treatment.

“I read a lot about cancer and different treatment procedures and had some knowledge about breast cancer from before, so I discussed different treatment options with the doctor, and decided which one was the best for me.”

Respondent 07 (2018-02-26)

In addition, poor knowledge about the causes of breast cancer could be identified during the interviews. Some women believed that cancer could be contagious and others that certain events caused the breast cancer. One respondent discussed the fact that many people in her community had cancer and she believed that the reason for this could be that the water in the district was polluted.

“Many people in the community have cancer; I am afraid that it might be something wrong with the water in the district.”

Respondent 20 (2018-03-08)

Poor knowledge about the causes, symptoms and treatment procedure of a health problem can affect the perceived need for healthcare and the care-seeking behaviour (Andersen, 2013). Perceived need is further determined by the perceived severity of symptoms and how they affect the daily life of the individual (ibid.). The degree of perceived need for breast cancer patients is thus dependent upon a myriad of factors, impacting the decision to utilise healthcare. The symptoms of breast cancer, however, highly vary depending on advancement and may be difficult to detect at an early stage (WHO, 2017a).

Distrust towards health practitioners

One of the reasons mentioned for not seeking healthcare - despite the discovery of symptoms, is general disbelief towards health practitioners. Although a few of the respondents were aware of the symptoms of breast cancer and were diagnosed during the examination, they delayed the initiation of treatment. Several women mentioned that they were informed about the symptoms

of breast cancer and the importance of getting an examination but that they still did not believe the oncologists when they received the final diagnosis. One reason mentioned for delaying initiation of treatment was that the patient did not believe that she could get cancer and that she thought the doctor might have misunderstood the results. As a result, she decided to get an examination at a different hospital.

“When the doctor said I had breast cancer I did not believe him so I went to see another doctor outside of the district.”

Respondent 01 (2018-02-19)

Studies indicate that disbelief towards health practitioners in a community can decrease the use of healthcare services (Hall et al. 2001; Thom et al. 2004). Several respondents expressed the lack of understanding of the healthcare system and where to access diagnostic services, which influenced their decision to see more than one health professional. Distrust could particularly be identified at the district level, while the general opinion about the treatment service and procedure at the specialised hospital was positive. Several patients mentioned that when they were referred to the K-hospital, they were confident that they were acquiring the appropriate treatment.

Financial and logistical barriers

Previous studies examining barriers to early diagnosis of breast cancer suggest that financial barriers are essential explanatory factors regarding the delay in diagnosis and treatment. The financial barriers identified during the interviews are cross-cutting across several levels of the socio-ecological model and will therefore be discussed at both individual and policy level.

Although financial barriers were not mentioned as an explicit reason for delaying utilisation of healthcare, several respondents stated that they were worried about not being able to cover healthcare expenses. A majority of the respondents were partially covered by public health insurance but still had to pay a part of the healthcare expenses by OOP. Despite efforts to reduce the OOP expenditure in Vietnam, the rates have continued to rise. The OOP rates for breast cancer patients are still very high due to low rates of health insurance and a lengthy treatment procedure. A review of OOP expenditure on cancer care found that it is considerably higher for

low-income groups, accounting for 75 % of the yearly income for lower income groups and 7% of the highest income group (Pisu et al. 2010: 577).

Respondents who were partially covered by insurance expressed financial constraints for accessing diagnostic and treatment services to a greater extent than respondents with full coverage. Many respondents further mentioned that they were primarily worried about the costs related to treatment. One respondent stated that she had to take a loan from the bank and use her savings to be able to pay the treatment expenses and other respondents expressed that they could cover the payments with financial support from family and friends.

“I was worried that I had cancer as I am not covered fully by health insurance. The treatment procedure for breast cancer is long and expensive so I was unsure if I could afford it when I got my diagnosis. My family said I should get the treatment anyway so I got a loan from the bank and used my savings to pay for the treatment.”

Respondent 01 (2018-02-19)

“I did not have insurance at first and did not want to go to the hospital. I then got insurance when I got the diagnosis [...] I am lucky that I have insurance now, I would not be able to get treatment if I did not have it.”

Respondent 09 (2018-02-27)

Studies examining costs for breast cancer treatment suggest that the general expenses for diagnosis, treatment and follow-up care are substantially higher for patients diagnosed at a more advanced stage (Barron et al. 2008; Hoang et al. 2013; Pallis et al. 2010). The estimated median cost for treatment in central Vietnam for a patient diagnosed at stage I is \$128.70, \$368.80 for stage II, \$ 684.10 for stage III and \$ 537.90 for stage IV (Hoang et al. 2013: 5). As the proportion of women diagnosed at a later stage is more eminent than in other comparable countries, the expenses are also higher. One respondent stated that she was very worried about not being able to pay for the treatment expenses as the cancer had advanced and spread to other parts of the body.

“The cancer has spread so the treatment is very expensive. I cannot work now so I am lucky that my daughter can support me, otherwise I could not afford the treatment.”

Respondent 14 (2018-03-02)

The treatment costs for breast cancer highly varies depending on the treatment option. It is estimated that chemotherapy - which is the most expensive option, costs \$22,000 per year in Vietnam (Jenkins et al. 2018:7). Several respondents mentioned that they impacted the choice of treatment and one woman stated that she chose the most expensive treatment, even though she had to pay a part of it OOP.

“I am a bit worried about money because I chose the most expensive and effective treatment.”

Respondent 08 (2018-02-26)

The ability to choose chemotherapy and other more expensive treatment options is therefore often dependent upon the ability to cover the treatment expenses, in addition to knowledge about different treatment options. Previous research found that the non-completion rate for breast cancer treatment is high in Vietnam compared to other countries. The dropout rate is higher among patients without health insurance, suggesting that breast cancer patients are facing economic hardship due to high OOP expenses (Jenkins et al. 2018).

Other financial aspects which could also impact the decision to utilise healthcare are non-medical costs for transportation and accommodation. The two specialist cancer hospitals are located in the large cities in Vietnam and patients in rural areas have to travel long distances to receive treatment. Several patients discussed financial difficulties due to accommodation costs in Hanoi and transportation costs for travelling to the hospital. As the treatment procedure for breast cancer is often highly time consuming and requires follow-up care, patients staying in rural areas have to travel to the hospital for longer periods of time. Several patients situated in rural areas stated that the bus fare to the hospital costs more than \$10 each time and that this is a barrier for accessing specialised healthcare.

“I am covered 100% by public health insurance but still worry about not having enough money. I pay a lot for staying in Hanoi and worry that I have to be here for a long time. The bus is very expensive so I have to take my motorbike and it takes me two hours to go to the hospital.”

Respondent 04 (2018-02-23)

Most of the respondents living in rural areas mentioned that an obstacle with accessing cancer services is the long distance from their village. Although some of the respondents had

motorbikes and were not affected financially by the long distance, they still expressed logistical difficulties for reaching the hospital. Previous studies further found that limited access to health services decreases healthcare utilisation (Field and Briggs, 2011; Hjortsberg, 2003).

“It takes me 4 hours to get to the hospital because I live 6 km away from the bus-station. I am very tired every time I have to go to the hospital.”

Respondent 03 (2018-02-21)

Many respondents were not able to work after being diagnosed with breast cancer, due to time-consuming treatment procedures. Instead, they have had to rely on financial support from family members and relatives. In addition, the household was affected financially as family members had to take care of them and could not work as much.

“When I get sick, I cannot work and earn money and my family have to take care of me and so they cannot work either.”

Respondent 13 (2018-02-28)

In previous research, indirect costs such as loss of earnings due to illness have been suggested as important aspects of financial barriers to early diagnosis and treatment. Several respondents stated that although they did not have any financial issues due to healthcare expenses, they faced financial hardship when they were diagnosed with breast cancer, due to a loss of income.

6.2 Interpersonal level

The knowledge level about a certain illness is often influenced by family and friends' perceptions about it and the advice that is given. Social support is, therefore an important determinant of healthcare utilisation (Andersen, 2013). Several respondents stated that they discussed their symptoms with family members and close friends, which impacted their perception about the seriousness of the symptoms.

Fear of cancer

Women who had a better understanding of the symptoms of breast cancer generally had a higher education and/or family and friends who were health practitioners. Some of the respondents had previous experience from cancer, which affected their decision to seek healthcare. Reconfirming findings from previous studies, the interviews indicate that fear is a factor impacting the path from symptom recognition to diagnosis. Patients who had experienced a relative or someone in the community that had been diagnosed with cancer had better knowledge about the symptoms but did not seek healthcare due to fear of the disease. A few respondents stated that they were scared about being diagnosed with cancer, after seeing other women being very sick.

“I waited three months after I found the symptoms before I went to the hospital. I knew it could be cancer but I was scared and did not want to believe it could happen to me.”

Respondent 19 (2018-03-08)

Other respondents were encouraged to get an examination at a hospital by friends and family who previously had survived breast cancer. Although these respondents had generally poor knowledge about the symptoms of breast cancer and where to access health services, they acquired social support which could provide them with information about symptoms and where to access diagnostic services.

“I mentioned that I found a lump to my friend who had breast cancer before and she encouraged me to see a doctor as soon as possible [...] several of my friends had breast cancer before and the information about symptoms has spread.”

Respondent 08 (2018-02-26)

One respondent consulted her daughter, who is a nurse, about the symptoms, which made her realise the importance of getting an examination at the district hospital. Furthermore, she discussed different treatment options with her daughter and made sure that she acquired the proper treatment procedure. Interpersonal support can thus act as an enabling resource to healthcare utilisation, but can also prevent the usage of health services due to misconceptions and fear.

“My daughter is a nurse and knows a lot about cancer so she told me to go to the hospital when I noticed the symptoms. She also helped me decide which treatment option was the best for me.”

Respondent 20 (2018-03-08)

Obligations

Sociocultural factors are often mentioned as an explanatory variable for delaying seeking healthcare. Previous studies suggest that women’s decision to seek healthcare is often influenced by their partner (Ensor and Cooper, 2004) which was also mentioned during one of the interviews. One respondent stated that she was aware of the symptoms of breast cancer at the time of recognition of symptoms but did not want to seek healthcare due to fear of not being able to take care of her sick husband.

“I did not go to the doctor when I found the symptoms. I knew of cancer from before because my husband has lung cancer. He was scared and told me that I would not be able to take care of him if I also got cancer.”

Respondent 19 (2018-03-08)

Other obligations such as taking care of children, elderly and the household often impact women’s healthcare utilisation and can delay the time of diagnosis (Ensor and Cooper, 2004). One respondent stated that it was expected of her to take care of a sick relative and that she was worried about how he would survive without her help. Several respondents further discussed that the diagnostic and treatment procedures were very time-consuming and that it prevented them from fulfilling household chores as well as taking care of children and family.

Stigma and misconceptions about breast cancer

Contextual predisposing characteristics, in terms of social values in a community, impact care-seeking behaviour. The general perceptions about an illness in a community can create stigma and prevent healthcare utilisation, creating access delay (Dey et al. 2016). Almost all respondents pointed out that there was a generally negative image of cancer diseases in their community and that many people believed that cancer was not curable. Low awareness about cancer and poor knowledge was particularly mentioned among women living in distant rural

areas. Several respondents stated that people tend to be very scared of cancer and prefer to not talk about it.

“Not many people know about cancer in my village and the ones that do are very scared of it.”

Respondent 04 (2018-02-23)

Inadequate knowledge about symptoms and causes of cancer create general misconceptions about the severity and treatment of cancer diseases. A few respondents stated that a common perception about cancer among people in their community was that it was contagious and that they needed to stay away from them. In addition, several women discussed the issue of people in their community questioning the reason for them getting cancer and if it could be due to certain events. One reason mentioned was that a lot of people died in the community and that it could intensify diseases like cancer.

“People in the community are very scared of cancer. They think it is contagious and they stay away from me.”

Respondent 12 (2018-02-28)

“Someone said that people died around me and that this could be a reason for the tumour growing bigger. I did not want to believe it but I still thought about it.”

Respondent 13 (2018-02-28)

Although several women stated that they were aware of the misconceptions, they still thought that this affected the general health-seeking behaviour in the community. Family and friends are often the initial source of health information in rural areas and depending on the support from the surrounding community, an individual perceives symptoms in different ways. Misconceptions in a community about a certain illness have in previous studies been suggested as an important explanatory factor for access delay (Kohler et al, 2016; Ogunkorode, 2017), and is therefore important to consider when analysing knowledge and attitudes at the interpersonal level. Personal values are affected by the social values in a community but are also dependent upon individual characteristics such as education, income and household situation (Andersen, 1995).

6.3 Institutional level

Although barriers identified at individual and interpersonal level help explain access delay in diagnosis, it is also important to consider factors at the institutional level, which impact the procedure of both diagnosis and treatment. Barriers at the institutional level primarily affect the supply-side, in terms of offering access to quality care. However, they might also influence the demand-side of healthcare utilisation and alter patient's perceptions of the need of health services (Andersen, 2014). Health systems in LMICs are generally weaker than in HICs and health services are often lacking in terms of quality, efficiency and equality (Anderson et al. 2011). Therefore, although symptoms are identified at an early stage, access to health services might not be available or adequate.

Poor knowledge among health practitioners

To be able to ensure timely diagnosis and treatment, general practitioners at primary care health centres should be able to identify symptoms and refer the patient to a specialised hospital for further examination or initiation of treatment. Delay in primary care could be identified during several interviews as respondents stated that their first contact with a general practitioner, following the discovery of symptoms, did not lead to a diagnosis or referral to a specialist. Reasons for delay included poor knowledge about the symptoms and low capacity in local health centres. One patient claimed that she noticed the lump in her chest early and went to a local health centre to get an examination, however, the general practitioner did not examine the lump further but said that the lump was benign and therefore not harmful.

“The doctor said that the tumour was normal, but the pain got worse so I went to a different doctor and they saw it was abnormal.”

Respondent 14 (2018-03-02)

Another patient experienced an intensification of symptoms following examination at a local health centre. When the health practitioner stated that the lump was not dangerous, she waited ten months before she went to a cancer centre in an urban area, where she was diagnosed with breast cancer.

“I went to a regular check-up at the rural health centre and they said it was just a normal lump and that it was not dangerous. It started to hurt more and more and after ten months I went to the cancer centre and they found the cancer.”

Respondent 06 (2018-02-23)

The quote above illustrates how inadequate referral systems and poor knowledge among primary care physicians can prolong the time interval from contact with a health practitioner to diagnosis, causing diagnostic delay. Although oncology departments primarily exist in urban areas, it is essential to strengthen rural health centre capacity to enable an effective referral system and investigation of symptoms (WHO, 2017a). In addition to barriers in enabling timely examination of symptoms at health centres, inadequate further examination at primary care centres in urban areas was illustrated in two interviews. A primary care physician did not investigate the lump found by one of the patients as she was young and breastfeeding at the time. This indicates poor knowledge about the high proportion of younger women being diagnosed with breast cancer in Vietnam.

“I was breastfeeding at the same time and felt a pain in the chest. I went to a doctor who did an ultrasound but he said it was because of the milk and that It was not dangerous. It got worse and worse and I went to a different hospital, where they found the cancer.”

Respondent 08 (2018-02-26)

Another patient experienced misinterpretation of symptoms when she went to the health centre in an urban area; she had previously removed a benign lump in her chest and the doctor said that it was only the wound from the surgery that was still sore.

“I had surgery four years ago in my chest and then it started to hurt but I thought it was just because of the surgery but went to the doctor anyway. I then had an ultrasound and they said it was only the scar from the surgery that hurt. Then four years later they found the tumour when I came back to the doctor.”

Respondent 18 (2018-03-05)

The perceived need to utilise healthcare services is reconfirmed by evaluated need from a health practitioner. If a physician fails to recognise symptoms and does not refer the patient to a specialist, the patient will perceive the symptoms differently (Andersen, 1995). However,

depending on the intensity of symptoms, the patient might decide to get an examination at a different health centre. Patients stated that when they were told that the symptoms were harmless, they first believed the doctor, but then when the pain intensified, they decided to get a second examination at a different health centre.

In addition to poor knowledge among general practitioners, a poor referral system at the primary care level can also be explained by low capacity at health centres. A study analysing diagnostic capacity at provincial hospitals in Vietnam found that 15,8% of the hospitals did not have established pathology departments and that the general diagnostic capacity was often lacking in terms of quality at other hospitals (Jenkins, 2018: 7).

Inequitable provision of health services

Horizontal equality, in terms of equal provision of health services for patients with the same need, independent upon income and socioeconomic status is an essential aspect of ensuring timely breast cancer diagnosis and treatment (World Bank, 2009). An unequal provision of health services could be identified among the interviewees. Two patients who had contacts at hospitals stated that it was easier for them to get an appointment than for other patients.

“I had met some of the doctors before when my husband got cancer and have been to the hospital, which helped the process when I got treatment.”

Respondent 19 (2018-03-08)

The patients further stated that it was important to arrive early in the morning to the hospital, as the appointments are scheduled according to the timing the person arrives. As a significant number of patient live several hours from the hospital, they often get scheduled later in the day.

“I know people at the hospital so I got an appointment and treatment quickly. Other patients have to be here early in the morning to get an appointment, even if they live far away.”

Respondent 07 (2018-02-26)

“It takes me 3 hours to get to the hospital and I get very tired. But I have to go because the first that come to the hospital get an appointment first.”

Respondent 11 (2018-02-27)

Personal contacts can thus act as enabling resources, affecting the access to treatment services at a hospital. Although this might not affect the general survival rates of patients getting treatment later during the day, it illustrates general shortcomings at the institutional level.

6.4 Policy level

The increasing incidence rate of cancer diseases in Vietnam has impacted the health policy agenda, extending the focus on control of NCDs. Although Vietnam does not have detailed cancer control plans (CCP), general CCPs have been established since 2008 (JAHR, 2015). The main objectives of the CCPs have been to reduce the prevalence and mortality rate from cancer and recommend specific activities in relation to the improvement of diagnostic and treatment capacity. The main themes of projects implemented are the following: screening for early detection, training and development of human resource capacity, an organisation of cancer registries and increased diagnostic capacity (ibid.).

Regulations at policy level impact barriers at the other levels, particularly the delivery of healthcare services at institutional level. The following section will discuss barriers at the policy level and how these affect early diagnosis and treatment of breast cancer, as well as how they influence the access to healthcare. In addition to an analysis of current health policies impacting barriers, interviews with key informants were used to acquire information about health practitioners' perceptions about the impacts of the essential cancer policies.

Early detection of breast cancer

Policies aiming to tackle the rising number of patients being diagnosed with an advanced stage of breast cancer has been one of the primary objectives of the cancer control projects implemented during the last decade in Vietnam. Screening programs have been implemented in several large cities and have succeeded at discovering a high number of breast cancer patients in early stages. However, the targeted group of these screening programs are mainly the urban population in large cities such as Hanoi and HCMC, potentially creating discrepancies in early detection between the urban and rural population (Jenkins et al. 2018). In addition, studies indicate that the screening programs lack the required diagnostic equipment and healthcare practitioners needed, due to a shortage of resources (JAHR, 2015). Several other constraints

regarding strategies for early detection of breast cancer could be identified during key-informant interviews.

“People are not aware of the symptoms of breast cancer, especially in rural areas where there is limited access to health services. Some screening projects have been implemented but this is not enough.”

Key informant 01 (2018-03-09)

Although awareness raising has been one of the primary objectives in the CCPs, it primarily concerns increasing the enrolment rate of screening programs. Few existing cancer projects specifically target awareness of symptoms of breast cancer, particularly so in rural areas.

Human resource and healthcare capacity development

Efforts to improve diagnostic and treatment capacity at oncology facilities has primarily been implemented through human resource investments. Training on early detection and prevention of cancer has been offered to health practitioners in a great number of districts (JAHR, 2015). However, the investments have solely targeted a few categories of health practitioners and courses have been offered primarily to nurses and oncologists (ibid.).

Despite significant efforts to reduce the uneven distribution of healthcare services, the healthcare system in Vietnam still faces several challenges in delivering equal provision of diagnostic and treatment services among the rural and urban populations. The MoH has been struggling with ensuring that all the oncology facilities follow the regulations and estimates indicate that the current healthcare capacity can only offer 30-40% of the cancer services required by the total population (JAHR, 2015). Health centres in rural and mountainous areas are facing difficulties in providing the cancer services needed due to a shortage of medical staff; thus limiting the access to specialised care to patients in need (ibid.). Inadequate healthcare and human resource capacity were further identified as barriers for timely diagnostic services during one of the key-informant interviews:

“The current system cannot handle the great number of cancer patients. There is a shortage of medical staff at the provincial level, especially pathologists. The treatment facilities and equipment is not sufficient [...] and it is also important that we get clear guidelines on cancer.”

Key-informant 02 (2018-03-09)

The MoH has made attempts to reduce the unequal distribution of healthcare practitioners in rural and urban areas and to decrease the high referral rate to urban hospitals with systems enabling support to health facilities with lower capacity. Projects such as satellite hospitals and Project 1816 provide human resource capacity to health facilities in rural and mountainous areas, with health practitioners from advanced facilities rotating to health centres with inadequate provision of medical personnel. Guidelines on oncology facilities have further been established, requiring four units of health practitioners to be available at every oncology facility: surgical, chemotherapy, radiotherapy and palliative care units. Evaluations of the performance of the guidelines, however, indicate that only 10% of oncology departments fulfil the requirements (JAHR, 2015: 77).

The organisation of cancer registries

To be able to compare regional variances in prevalence and mortality as well as monitor and evaluate activities implemented, cancer registries are needed (WHO, 2017a). Following the introduction of CCPs, an expansion of cancer registries was conducted in nine out of 58 provinces in Vietnam (JAHR, 2015: 224). However, only the cancer registries in Hanoi and HCMC were quality certified by the International Agency for Research on Cancer (IARC). Evaluations further indicate that information about methods is absent and that the databases do not include mortality, but only incidence rate (ibid.). During interviews with key-informants, insufficient coverage and measures of cancer registries were mentioned as a critical hindering factor for the establishment of a system for early diagnosis and treatment of breast cancer.

“The existing cancer registries highly vary in quality depending on hospital and it is difficult to ensure that the data is correct and comparable [...] MoH has to regulate cancer registry reporting to ensure that the coverage and quality are improved.”

Key informant 01 (2018-03-09)

A lacking cancer registry system with poor coverage rate and limited control of quality is not unique for Vietnam and is common among LMICs (Anderson et al. 2011). It could hinder the development of successful cancer control measures in several ways. A comprehensive cancer registry could, in addition to incidence and mortality rate, also include information about disease burden in terms of DALYs as well as descriptive data which could be used for analysis of risk factors (Jedy-Agba et al. 2015). Evaluating the effects of different policy measures with the use of cancer registries can highlight discrepancies between intended objectives and outcomes and create incentives for further resource allocation (ibid.).

Health insurance coverage

Despite vast improvements in insurance coverage and subsidy rate for the poor and near-poor population in Vietnam, a substantial part of healthcare expenses is still paid OOP. The Universal Health Coverage Plan which was initiated by the MoH in 2012 aimed to increase the social health insurance rate to 70% by 2015 and 80% by 2020, as well as reduce the OOP expenditure to less than 40% by 2020 (World Bank, 2014: 2). Although the coverage plan specifically targeted poor and near-poor groups, the insurance enrolment rate for the near-poor was in 2012 still only 25%. Estimates indicate that 14% of the Vietnamese population is considered to be near-poor, and a significant proportion experience a financial burden due to high healthcare expenses (Vuong et al. 2014:5).

This could be explained by the fact that the poor are fully subsidised, while the near-poor have to pay for an insurance premium and cover the majority of health expenses OOP (Vuong et al. 2014). Key informants further stated that the low coverage rate of the near-poor population is one of the structural challenges in the cancer service system, which impacts the possibility for patients to utilise healthcare.

“It is clear that many patients cannot afford the healthcare expenses. They are not considered as poor and must pay a part of the costs by themselves, even if they are covered by social health insurance for the near-poor.”

Key informant 02 (2018-03-09)

The insurance for the near-poor population is a part of the voluntary enrolment group, which implies that patients must apply for the insurance individually. This type of enrolment has in

previous studies been considered as problematic for ensuring universal health coverage (Kutzin, 2012). It is dependent upon knowledge about the implications of the insurance and how it varies depending on factors such as income and household size (Nguyen and Nilson, 2017). Several patients in the near-poor group stated that they were unsure if they were covered by insurance and what the coverage implied. This might be explained by a complex insurance scheme which is dependent upon a great number of factors. This barrier is consistent with other studies in Vietnam, which found that there is a generally low awareness about insurance schemes among the near-poor population (ibid.).

7. Strategies to target identified barriers

Although the barriers identified during the interviews might not be representative for Vietnam as a country, they provide valuable insights regarding patients, oncologists and researcher's perceptions about challenges in relation to early diagnosis and treatment of breast cancer. As a response to the barriers identified, the following section will review the current research concerning strategies to tackle different challenges in LMICs and strengthen early diagnosis and treatment capacity. However, due to the limited scope of this thesis, all aspects of policy implications and strategies will not be covered. Healthcare policy is highly path-dependent and it is, therefore, challenging to initiate structural changes. This section will thus only provide an overview of relevant policy implications and primarily focus on improvements in relation to awareness raising and training of healthcare personnel.

7.1 Policy implications

During interviews with key-informants and an analysis of relevant health policy, several shortcomings were identified at the policy level. The healthcare system in a country and the ability to deliver timely healthcare of high quality is dependent upon available resources and general health expenditure, which is why strategies for early detection highly vary between LMICs and HICs. Studies suggest that a comprehensive national cancer plan is essential for improving breast cancer outcomes in a population and promote early detection and timely treatment (Anderson et al. 2011). Although Vietnam has a national cancer plan in place, it is not very detailed, and the quality of implementation highly vary geographically (Jenkins et al. 2018). The difficulty in monitoring and evaluating the activities implemented is further

dependent upon an established national cancer registry, which is considered as a crucial step in ensuring the quality of the strategies used and evaluate morbidity, mortality and cancer stage (Corbex et al. 2012). As only two of the cancer registries in Vietnam have been quality certified, and the measures used differ between provinces, comparisons might be difficult.

In addition to organisational challenges in establishing early detection and diagnosis capacity, financial obstacles occur across all the level of influence, which requires interventions at policy level. Financial protection measures for vulnerable groups, as well as equity in healthcare delivery, are essential aspects of limiting critical delays of more than three months, and experts advise that it should be prioritised in all countries (Anderson et al. 2011). Guidelines for cancer services are further needed to ensure that resources are allocated appropriately at the provincial level. Although financial protection measures are dependent upon the available healthcare budget, a number of measures can be implemented to increase the healthcare expenditure, including an increase in governmental subsidies (ibid.). Despite the current financial prosperity in Vietnam, the current expenditure might not be able to cover the expenses of all vulnerable groups, which is why NGOs and other external actors continue to play an important role in the development towards full healthcare coverage of the population in LMICs (Andersen et al. 2011; Love et al. 2012).

7.2 Early detection of breast cancer

Training of healthcare personnel

Both interviews with patients and key-informants suggest that there is a low general knowledge about early diagnosis among health professionals, which can delay the time of diagnosis and initiation of treatment. The low awareness and misdiagnoses could primarily be observed at primary care level, which is the first contact within the healthcare system. Health practitioners at the primary care level thus play an essential role in identifying symptoms at an early stage (WHO, 2017a).

As recommended by the WHO, strengthening knowledge about early diagnosis among primary care practitioners can be accomplished through educational activities (WHO, 2017a), and should be included in all early detection strategies (Anderson et al. 2011). Healthcare professionals should receive education about early signs of cancer and how to perform low-

cost examination techniques (Corbex et al. 2012). Although breast cancer symptoms might not be specific, it is essential that “red flag” symptoms are acknowledged and examined. Appropriate and effective examination of breast cancer symptoms at primary care level is further dependent upon the availability of diagnostic equipment, early referral capacity and enough time to investigate symptoms (WHO, 2017a).

Community awareness

Efforts to increase community awareness and knowledge about breast cancer in Vietnam have primarily focused on implementation and expansion of screening projects. Although the screening projects only cover a fraction of the population, the government aim to extend it to a population coverage in the future (Jenkins et al. 2018). The harms versus benefits of a nationwide screening in LMICs has been highly debated, due to limited healthcare budgets, unclear benefit versus harm ratio, presentation of symptoms at an early age and low coverage as well as participation rate in the screening programs (Anderson et al. 2011; Corbex et al. 2012). Studies conducted in LMICs indicate that screening programs in these countries seldom reach the goal of a 70% coverage of the target population, which is recommended by the WHO (Anderson et al. 2011; WHO, 2017a). Factors such as low literacy further cause low participation in diagnostic and treatment procedures following screening (Corbex et al. 2012). Although it is not possible to evaluate the screening programs in Vietnam due to a limitation of data, the evaluations of screening programs in other low and middle-income settings suggest that the screening programs are often insufficiently implemented (Murilo et al. 2008; Pisani et al. 2006).

A suggested alternative for national screening programs in LMICs is to focus on establishing annual clinical breast exams at diagnostic centres (Anderson et al. 2011). A large randomised trial analysing clinical breast examinations in India indicate that it can be used, in combination with an effective treatment procedure, to improve outcomes in stage at diagnosis and survival rate (Mitra et al. 2010). If practiced regularly, it can be as efficient as mammography screening but to a fraction of the costs of national screening programs (Anderson et al. 2011).

However, to be able to increase the healthcare utilisation following symptom presentation, irrespective of cancer control efforts, awareness raising among communities is needed

(Anderson et al. 2011). Interviews with patients indicate that there might be a low knowledge level about symptoms of breast cancer, and general misconceptions about cancer diseases. According to the WHO, initiatives to raise awareness among communities should focus on providing knowledge about cancer and point out that breast cancer is treatable. It is also recommended that awareness programs should include local breast cancer survivors, physicians, politicians and opinion leaders. Community health workers can further be used to inform about symptoms and health services. A project that involved community health workers in Malaysia succeeded in reducing the share of late stage at diagnosis from 60% to 30% following a four-year project (Devi et al. 2007). Printed and social media can be used to improve health literacy, share knowledge about symptoms and reduce misconceptions and stigma about breast cancer. The outreach programs should, however, adjust culturally to ensure that they are appropriate in the community (WHO, 2017a).

In addition to informing about breast cancer symptoms, the awareness campaigns are also advised to include information about access to health services and discuss barriers for utilising healthcare in the community. These discussions can also be used for addressing barriers identified, for example, rearrange the location of a health centre if logistical barriers exist (WHO, 2017a).

8. Concluding discussion

This study has aimed to contribute to the research field of early diagnosis of breast cancer in Vietnam, by examining the barriers identified by breast cancer patients and key-informants in Hanoi. Although the barriers are presented according to the different levels of influence in the socio-ecological model, several of the barriers are cross-cutting across different levels, thus requiring a holistic approach. Barriers identified at the interpersonal level partly involve the influence of larger groups and beliefs of the community. As the discussions of these barriers intersected during the interviews, they are grouped as one level of influence.

Categorising the different barriers following the socio-ecological model has illustrated how barriers at different levels interact and how structural factors at policy, institutional and interpersonal level affect individual healthcare utilisation and perceptions about breast cancer. This study has aimed to adjust the model according to the barriers identified and integrate

other theories, to fully be able to explain the healthcare utilisation of breast cancer patients. Concepts of the Healthcare Utilisation Model were thus employed in order to analyse the mechanisms which promote or prevent certain barriers to occur.

Although correlations cannot be ensured with this study, the identified barriers could potentially create both access and diagnostic delay. Several significant findings emerged during the analysis and barriers creating access delay were primarily recognised at the individual level. General distrust towards health practitioners was mentioned as a barrier for early diagnosis as several women did not believe the health practitioners when they received their diagnosis, which delayed initiation of treatment. Distrust was particularly identified among health practitioners at the district level. In addition, as a majority of the respondents were situated in rural areas, logistical barriers for reaching the hospital could be identified. Many of respondents had to travel several hours to access cancer services. Although the respondents did not state that this affected their decision to utilise healthcare, research indicates that limited access to health services decreases healthcare utilisation. Policy measures have primarily focused on the expansion of services in larger cities, which could potentially create discrepancies between rural and urban areas.

One of the main barriers identified is low awareness among patients, health practitioners and among communities, which impacts women's perceptions of breast cancer symptoms and their healthcare-seeking behaviour. This finding is not unique to Vietnam, and previous studies have found that a low awareness is one of the key-barriers to early diagnosis of breast cancer in LMICs. Traditional healing options are still prevalent in rural areas in Vietnam, and several respondents initiated an alternative treatment, which impacted the time of diagnosis. Studies with similar findings in other LMICs suggest that the reason for alternative treatments is poor access to health services, low awareness and misconceptions about cancer diseases. Low awareness among health practitioners was identified as a barrier for early diagnosis as several patients had to contact more than one health professional before getting a diagnosis. The combination of poor knowledge among health practitioners and low primary care capacity could potentially create diagnostic delays for breast cancer patients, which is why efforts in strengthening primary care capacity should be prioritised.

This study further suggests that an explanation for the low awareness among respondents is few awareness-raising initiatives at the policy level, due to focus on breast cancer screening

projects. LMICs such as Vietnam, which have experienced immense economic growth during the past century, often focus on the expansion of screening programs, without considering the harms and cost-effectiveness of screening programs. Previous research states that national screening programs are a “golden standard” for many LMICs, even though other approaches are often more suitable and cost-effective.

Few initiatives have aimed to improve the general awareness among communities in Vietnam. Therefore, to overcome the barrier of a low general awareness, more focus should be given to awareness-raising activities, particularly in rural areas. Low awareness and poor referral systems among health practitioners could further be explained by supply-side barriers such as low healthcare and human resource capacity. As stated by one key-informant, detailed breast cancer guidelines are currently missing in Vietnam, which is needed to ensure timely and effective pathways in the healthcare system.

This study further argues that financial barriers are of great importance for explaining delays in the pathway to breast cancer diagnosis in Hanoi, which could be explained by a low health insurance coverage, particularly among near-poor groups. Low insurance enrolment rates increase the OOP expenditure rates, limiting protection against catastrophic health expenditure. However, even though many patients were at least partially covered by health insurance, they still had to pay a part of the healthcare expenses OOP. A significant number of respondents were worried about payments for cancer services, especially the costs related to breast cancer treatment as the treatment procedure is very long and expensive. Depending on the treatment and the advancement of the disease, the OOP costs for breast cancer treatment highly vary in Vietnam. In addition to financial barriers in terms of medical expenses, several respondents stated that indirect costs due to loss of earnings put a strain on the household economy. Non-medical costs regarding expenses for travelling to the hospital and accommodation in Hanoi were further mentioned as financial limitations for accessing treatment services.

In addition, the findings indicate that the surrounding environment and community of an individual profoundly impacts the healthcare-seeking behaviour. To be able to explain the delay in breast cancer diagnosis in Vietnam, several barriers at the interpersonal level are important to acknowledge. Empirical data from this study indicate that social support from family, friends and neighbours can either hinder respondents from seeking healthcare due to

household obligations, fear or misconceptions or provide support concerning advice about symptoms and/or financial support. Horizontal inequity was further identified at the institutional level during the analysis, as personal contacts could enable access to health services.

While attempting to explain barriers to early diagnosis of breast cancer in Vietnam, this study focuses solely on the perspectives of patients in one hospital in Hanoi. Additional studies in Hanoi and Vietnam need to be conducted to ensure that the results are not only valid for a particular group. In addition, studies using quantitative or mixed methods to examine timeframes for the different delays could be beneficial, to be able to quantify the delays and identify appropriate interventions. However, as with a majority of qualitative studies, the aim with this study was to acquire accumulative knowledge of a specific phenomenon, which could point the right way towards additional studies, as well as policy implications. No qualitative studies have previously examined breast cancer patient's perspectives about barriers to early diagnosis and cancer service in Vietnam, which is why this study still contributes to bridging the gap of knowledge about early diagnosis of breast cancer.

In conclusion, this study has identified several barriers which impact the access to cancer services and could explain the delay in utilisation of healthcare, diagnosis and treatment. By interviewing breast cancer patients, individual perceptions about cancer services were highlighted, which has in previous research been suggested as an essential aspect of ensuring timely and effective cancer services. Following an analysis of prior research of cancer services in LMICs, this study has suggested strategies to tackle the essential barriers in Vietnam and discussed policy implications. However, to be able to decide on policy measures, additional research on barriers to early diagnosis of breast cancer need to be conducted in Vietnam.

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Appendix A. Information guide⁵

Introduction

My name is _____. I am here performing a study that focus on barriers that causes delays in cancer diagnosis.

This consent form will give you information about the study and we would like to invite you to be part of it. You do not have to decide today whether you want to be part of the study or not. Before you decide, you can talk to anyone you feel comfortable with about this study.

The consent form may have words that you may not understand. Please feel free to stop me as we go through the information and I will take the time to explain. If you have more questions at the end, you can ask me or anyone else in the study team.

Purpose of the Research

A lot of cancers are being discovered late in your community/area/country preventing people from getting good treatments and become healthy again. We want to find ways that can prevent cancer being diagnosed late. We believe you as a cancer patient can help us by telling us the challenges you experienced when seeking medical care. We want to learn if people in your community know what causes cancer and what ways people try to treat or cure cancer. We also want to learn if people with cancer experience personal barriers, such as difficulty paying for medical visits or experience healthcare barriers, such as long waiting list to get a diagnosis test. Knowing and understanding the possible barriers your community experiences will help us find better ways to get cancer diagnosed early. We can assure that there are no right or wrong answer, therefore, you can share your exact experience with cancer freely. We also can assure you that we will not pass judgement when you share your experience.

Type of Study Intervention

This study will involve your participation in an interview that will take approximately 30 minutes.

Voluntary Participation

Your participation in this study is completely voluntary. You decide whether or not you want to participate. If you decide not to participate in this study, it will not affect the medical services you receive at the hospital. The services will continue and nothing will be changed.

Procedures

We would like you to participate in our study. If you accept our invitation to participate, we will ask you to be part of an interview. If you are not able to participate in the interview at this moment, we can arrange a later time for us to meet and complete the interview.

The interview will be performed by me. During the interview, I or another interviewer will sit with you at a comfortable place or in a private room at the hospital/clinic. No one else will be present but the interviewer. You may ask any questions or concerns you have during the interview. You may also choose not to answer any questions and you may say so to the

⁵ Acquired from WHO (n.d.).

interviewer. The interviewer will continue with the next question. The entire recorded interview will be confidential and only people from the study team will have access to the information. Your identity will be protected by using an identification number instead of your name. During the study the recorded information will be kept secure in a locked and protected room.

The entire interview will be tape-recorded, but no one will be identified on the tape and only people from the study team will have access to the tape. The tapes will be destroyed after 12 weeks.

Risk

We are asking you to share some personal and confidential information, and you may feel uncomfortable talking about some of the topics. You don't have to answer any questions that make you feel uncomfortable. You don't have to give us any reasons for not responding to any questions or refusing to take part of this interview.

Benefits

There will be no direct benefit to you, but your participation will likely help us find out more about what ways can help prevent delays in cancer diagnosis and develop policies and healthcare services to improve diagnosis and treatment in your community.

Confidentiality

The study being done at the hospital/clinic may draw attention and if you participate other patients and staff may ask you questions about the study. Information about you will not be shared with the hospital/clinic or the community. Your identity will be protected using a number and only the study team will have access to your information. The obtained information will be secured in a protected place using a lock and key.

Sharing the results

Nothing you share with us today will be shared with anyone outside of the study team. Your information will be kept unidentified and protected to the public.

Who to Contact

If you have any questions or concerns about the study at a later time, you can contact [Name] at [phone number/e-mail address].

Appendix B. Certification of consent⁶

For literate participants

I have been invited to participate in a study about identifying barriers to early cancer diagnosis in my community. I was given an information sheet about the study. I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant _____

Signature of Participant _____

Date _____

Day/month/year

For Illiterate participants

The foregoing information on the information sheet has been read aloud to the participant. Time and opportunity was given to the potential participant to ask any questions or voice any concerns. I answered the questions and address the participant's concerns to my best abilities. The whole conversation was recorded using tape-recorder ____.

- Patient provided a verbal consent to participate in the interview (consent recorded with the tape-recorder)
- Patient provided a verbal decline/refusal to participate in the interview (refusal recorded with the tape-recorder)

Print Name of Researcher/person witnessing the verbal consent _____

Signature of Researcher /person witnessing the verbal consent _____

Date _____

Day/month/year

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands the interview procedure and the aim of the study.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____ Day/month/year

⁶ Acquired from WHO (n.d.).

Appendix C. Interview guide⁷

Patient identification number ||||

Date of interview/...../.....

Demographics

Stage at diagnosis

Date of birth (dd/mm/yy)/...../.....

In what type of community did you live most of your life?

Urban Rural

What is the highest level of school you attended?

No formal schooling

Primary school

Secondary school

University

Do you have any kind of health insurance?

No Health Insurance

Private Health Insurance

Public Health Insurance

A combination of both public and private health insurance

Who pays the majority of your medical expenses until now?

Out of pocket (You or your spouse)

Your family/friends

Health insurance

Barriers to early diagnosis

How did you discover that you have breast cancer?

When you discovered the symptom, what did you think and do? Did you contact any health professionals?

Could you please describe in detail the path from that you discovered symptoms until today.

⁷ Questions based on WHO (n.d.).