THREE PERSPECTIVES ON SCREENING-DETECTED ABDOMINAL AORTIC ANEURYSMS IN A SWEDISH CONTEXT: A QUALITATIVE SINGLE CASE STUDY WITH EMBEDDED UNITS

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Three Perspectives on Screening-Detected Abdominal Aortic Aneurysms in a Swedish Context: A Qualitative Single Case Study with Embedded Units

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PREFACE

This thesis sheds light on abdominal aortic aneurysms (AAA) detected via screening from three different perspectives: men living with this diagnosis, their partners and the healthcare professionals who screen and care for the men and their partners. I myself have been working at Skåne University Hospital with patients with cardiovascular diseases as a nurse since 2004, first as a registered nurse and later as a nurse anaesthetist. Caring for patients with vascular diseases is a complex challenge because they suffer from multiple diagnoses. Nurses' competence is vital for the patients' recovery, which requires constant updates and improvements. I find the nature of this work interesting, challenging but also rewarding. To be diagnosed with an AAA can cause worries for the patients and their families and it can change their lives forever in different ways. As healthcare professionals, we play an essential role in how patients' and their families' lives are affected by this diagnosis.

In 2010, the vascular clinic in Malmö at Skåne University Hospital introduced a screening program for AAA in 65-year-old men. Through the introduction of AAA screening, we met a new group of patients, the men under surveillance and their families, with their care needs. This required additional knowledge for the professionals. I hope that the content of this thesis can help us to learn from the perspective and experiences of these men and their partners and empower healthcare professionals to apply this knowledge to further improve care for their patients.

ABSTRACT

Background

An abdominal aortic aneurysm (AAA) is an abnormal widening (≥3 cm) and weakening of the abdominal part of the aorta. It is a relatively common condition in the older male population. Notably, males have a higher risk of developing the condition if they previously used or currently use tobacco. Increasing age and a family history of AAA also increases the risk of developing this condition. Most AAAs are asymptomatic until rupture. AAA rupture is a major consequence associated with high mortality. Therefore, screening of the abdominal aorta via ultrasound has been introduced in some countries. In Sweden, all 65-year-old men are invited for AAA screening. If an AAA is found, they remain under surveillance with regular follow-ups until the AAA reaches a diameter of 55 mm. Thereafter, they are offered an elective surgery of the aneurysm.

Through screening, the men become aware of a potentially threatening diagnosis that can affect and change their life situation and impact their quality of life. Life-threatening diagnoses affect patients' and their families' lives in various ways. Since an AAA diagnosis can be considered life-threatening, it can affect an entire family. However, it remained unclear how the lives of AAA patients' partners are affected.

The overall aim of the thesis was to explore, describe and contrast experiences and perspectives of screening-detected AAA in a Swedish context from the perspective of affected men, their partners and health care professionals.

Method

To meet the aims of this study, a qualitative single case study with embedded units was used. The case was described as "Perspectives of screening-detected AAA" and the three embedded units were the men, the partners and health care professionals. The data were collected through individual interviews and focus group interviews. The men were purposively recruited from a local screening database (Filemaker). Although a total of 27 interviews were conducted, the analysis was based on 25 interviews since two were excluded due to technical problems and one man was unaware of his aneurysm. The partners were recruited using a convenient sampling method after obtaining consent from the men. In total, 21 interviews were conducted with partners. Health care professionals were recruited through a purposive sampling method. Invitations containing a brief explanation of the study were distributed to contacts at vascular clinics in Sweden. A total of five interviews were conducted with professionals working with AAA screening.

The interviews were conducted following semi-structured interview guides. After obtaining consent from the participants, the interviews were digitally recorded and verbally transcribed in Swedish. The goal of qualitative data analysis extends beyond the visible data gathered from interviews by searching for patterns. Qualitative content analysis is a commonly used method for analysing data to gain a deeper understanding of a phenomenon. Data analysis for the present study was conducted

within each embedded units and followed by a cross embedded units analysis. An inductive approach was used for within analyses of data collected from partners. The data were divided into chunks and labelled with codes that reflected the meaning of each chunk. The codes were compared and chunks with the same meaning were organised into subcategories and categories.

The within analysis for the men was conducted in a similar manner. Chunks were labelled with codes and then organised under the same labelled categories as the partners. Furthermore, based on the categories created from the two aforementioned within analyses, a deductive manifest analysis was performed using data from interviews with health care professionals.

Finally, a cross-analysis was conducted to compare content from the three embedded units. Portions of the analysed text from the men and partners were combined in matrices, and their differences were highlighted. These contrasts were summarised in a common text. Based on this text, the health care professionals' viewpoints, descriptions and opinions were deductively highlighted. The cross-analysis was presented as an interpretive text followed by short narratives.

Findings

The findings related to partners' perspectives of AAA were presented under three categories: 1) *Experiencing the unexpected*, 2) *Being reminded of fragility* and 3) *Balancing a changing relationship.* The category “Experiencing the unexpected” consists of two subcategories: 1) *Shock and emotional reactions* and 2) *Peripheral to first-hand information.* The category “Being reminded of fragility” consists of three

subcategories: 1) *Reminders during daily activities*, 2) *Waiting in uncertainty* and 3) *Ambivalent feelings about surgical treatment.* The third category, “Balancing a changing relationship”, consists of three subcategories: 1) *Supporting a healthy lifestyle*, 2) *Protecting roles* and 3) *Preparing for the worst.* For the partners, living with men diagnosed with an AAAs involved experiencing widespread recurrent worries. Furthermore, the analysis of the men's experiences of living with a screening-detected AAA is described under the three aforementioned categories that are common to the men and the same with the health care professionals’ deductive manifest analysis. The cross-analysis of the three embedded units is illustrated as a screening surveillance journey and presented under two subcategories: 1) *Navigating through a new life situation*, 2) *Anchoring to a life with an AAA.* Under each subcategory, an interpretation focusing on the contrasts between the embedded units is presented, which is followed by a short narrative story that aims to illustrate the participants' experiences.

Conclusion

This study has revealed a deeper understanding of three perspectives on screening-detected AAAs. Awareness of a screening-detected AAA affected the diagnosed men and their partners’ lives in various ways. While the experiences were recurrent, they also moved patients towards adjusting to a new lifestyle. Although uncertainty existed among the men and the partners during the process of adjusting to a new life situation, this uncertainty was appraised as either dangerous or an opportunity, which affected their outcome. Since the participants are affected by the screening surveillance and the awareness of the AAA, it indicates the need for further interventions by health care professionals to improve support and information for those living with a screening-detected AAA.

Keywords: Abdominal aortic aneurysm, experiences, health care professionals, men, partners, screening, uncertainty, QOL impacts.

LIST OF PRESENTATIONS AND PUBLISHED WORKS

Refereed journal articles published from the work in this thesis

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2. Ericsson, A., Carlson, E., Ching, S.Y., Molassiotis, A., & Kumlien. (2020). Partners' experiences of living with men who have screening-detected abdominal aortic aneurysms: A qualitative descriptive study. *Journal of Clinical Nursing*, 29, 3711–3720. doi: 10.1111/jocn.15399

Conference presentations

1. Ericsson, A., Kumlien, C., Ching, S.Y., Carlson, E., & Molassiotis, A. (2019). Impact on quality of life of men with screening-detected abdominal aortic aneurysms attending regular follow ups: A narrative literature review.
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Oral presentation
The European Society for Vascular Surgery
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1. Ericsson, A. Quality of life of participants undergoing screening for abdominal aortic aneurysm and attending regular follow-ups. A Literature Review.
School research seminar (Oct 2016). School of Nursing, The Hong Kong Polytechnic University, Kowloon, Hong Kong.

2. Ericsson, A. Towards a systematic development of an intervention for further support in an abdominal aortic screening environment: A proposal.
School research seminar (April 2017). School of Nursing, The Hong Kong Polytechnic University, Kowloon, Hong Kong.

3. Ericsson, A. Impact on quality of life of men with screening-detected abdominal aortic aneurysms attending regular follow ups: A narrative literature review.
PhD Research Seminar (May 2017). Department of Care Science, Malmö University, Malmö, Sweden.

4. Ericsson, A. The data collection process of a qualitative case study. School research seminar (April 2018). School of Nursing, The Hong Kong Polytechnic University, Kowloon, Hong Kong.

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TABLE OF CONTENTS

INTRODUCTION

LITERATURE REVIEW

METHODOLOGY

RESULTS

DISCUSSION

IMPLICATIONS & CONCLUSIONS

APPENDIX

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

In alphabetical order

AAA	Abdominal aortic aneurysm
CASP	Critical Appraisal Skills Programme
CIOMS	Council for International Organization of Medical Science
CAQDA	Computer-assisted qualitative data analysis software
CT	Computed tomography
EQ 5D	EuroQoL Five Dimension
EVAR	Endovascular aortic repair
FU	Follow-ups
GHQ	General Health Questionnaire
HADS	The Hospital Anxiety and Depression Scale
HCP	Health Care Professionals
MRI	Magnetic resonance imaging
QCA	Qualitative content analysis
QCS	Qualitative case study
QOL	Quality of life
QD	Qualitative description
RCT	Randomised controlled trial
RN	Registered nurse
SBU	Swedish Agency for Health Technology Assessment and Assessment of Social Services
ScreenQL	Screen Quality of Life Questionnaire
SF-36	Short Form Health Survey
STAI	Spielberger State-Trait Anxiety
U/S	Ultrasound
WHO	World Health Organization

CHAPTER ONE

INTRODUCTION

1.1 Introduction

Abdominal aortic aneurysms (AAAs) are relatively common among older men. Notably, a correlation exists between increased AAA diameter, AAA rupture and death. To prevent ruptures, screening of the abdominal aorta has been introduced.

This chapter will present background information on the medical diagnosis of AAA, which is the focus of this doctoral thesis. Abdominal aortic screening, its side effects and the ethical criteria that all medical screening must meet will also be described. Furthermore, the overall aim of this thesis and its structure will be presented at the end of this chapter.

1.2 Abdominal aortic aneurysms

1.2.1 Anatomy and definition

The aorta is the main artery of the body and transports oxygenated blood from the left ventricle of the heart to the rest of the body. The ascending aorta begins at the aortic valve of the left ventricle, continues into the aortic arch and extends to the descending aorta. The aorta passes through the diaphragm via the aortic hiatus. Inferior to the diaphragm, the aorta is called the abdominal aorta (Martini et al., 2015). The abdominal aorta is often divided into the suprarenal, above the renal arteries and infrarenal abdominal aorta, below the renal arteries (Wanhainen et al., 2019). The diameter of the aorta varies depending on gender, age and weight, but has a greater diameter in the abdominal cavity (Bengtsson et al., 1996). The word "Aneurysm" means widening and is defined as "a permanent and irreversible localised dilatation of a vessel" (Sakalihasan et al., 2005, p. 1577). An AAA is most commonly defined as an abnormal widening of the abdominal aorta with a diameter of ≥30 millimetres (mm) (Wanhainen, 2008; Wanhainen et al., 2019). Another suggested AAA definition is an abnormal widening of the abdominal aorta that is 1.5 times larger than the normal diameter (Wanhainen et al., 2019). To be defined as a true aneurysm, all three layers of the aortic wall, the tunica intima, media and adventitia, should be involved in the widening (Wanhainen et al., 2019). The most common location for an AAA is the infrarenal part of the aorta (Ayari et al., 2001; Blanchard, 1999) and AAAs are more common than aneurysms in the thoracic aorta (Isselbacher, 2005) (Figure 1).

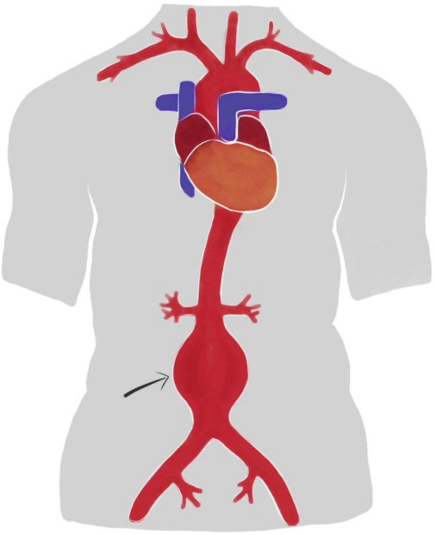

Figure 1 Illustration of an abdominal aortic aneurysm.

1.2.2 Risk factors for developing an AAA

Abdominal aortic aneurysms are common in developed countries. Notably, 2 to 4% of men over 65 years in the United States of America (USA) and Europe have an AAA (Lederle, 2011; Wanhainen et al., 2019). However, the prevalence of AAA for the same age group in Sweden (1.5–1.7%) and England (1.3%) is lower ; (Jacomelli et al., 2016; Wanhainen et al., 2016).

There are several known risk factors for developing an aneurysm, such as smoking, increasing age, male gender and heredity (Kent et al., 2010). Smoking is the most important risk associated with an AAA, which results in a six to seven times greater risk for current smokers (Kent et al., 2010; Singh et al., 2001). Overall, 90% of patients with AAAs have a history of smoking (Powell & Greenhalgh, 2003). The association between AAA and smoking is stronger than for smoking and other diseases, except for lung cancer (Forsdahl et al., 2009). The duration of smoking is also associated with an increased risk of developing an aneurysm. Each smoked year increased the risk of developing an aneurysm by 4% (Wilmink, Quick, & Day, 1999). Aneurysms expand at nearly double the rate for smokers when compared to non-smokers or former smokers. Notably, smoking cessation decreases the risk of developing an aneurysm by 3.3% for every smoke-free year (Kent et al., 2010; Powell & Greenhalgh, 2003). Strong associations between AAA and hypertension, arteriosclerosis, other cardiovascular diseases and obesity have also been revealed (Kent et al., 2010; Toghill et al., 2017). Exercise and diets with fruits, nuts and vegetables have been shown to reduce the risk of developing an AAA (Kent et al., 2010). Female gender is also associated with a decreased risk of developing an aneurysm. The risk of having an aneurysm is four to six times greater among men than women (Svensjö et al., 2013). Furthermore, patients with a family history of AAA have an increased risk of developing AAA, especially among the first degree of the family members (Isselbacher, 2005; Larsson et al., 2009). The prevalence of aneurysm development increases for those over 55 years of age (Blanchard, 1999).

1.2.3 Diagnosis of AAA

Most AAAs are asymptomatic until they rupture, which makes them difficult to diagnose. Abdominal aortic aneurysm is often detected via routine examination or by chance during an investigation for other diseases using computed tomography (CT) or magnetic resonance imaging (MRI). Therefore, AAA screening has been introduced in some countries. Notably, ultrasound (U/S) is a sensitive, cost-effective and non-invasive method with high specificity for diagnosing AAAs (Isselbacher, 2005).

1.2.4 Treatments for AAA

Two surgical techniques are available for treating AAAs: open surgery and endovascular aortic repair (EVAR). The choice of technique depends on the AAA morphology, the patient's overall risks with other comorbidities and whether the patient has undergone previous abdominal operations (Wanhainen et al., 2019).

Open surgery

Since Dubost et al. (1952) introduced the operative technique in the 1950s, open surgery has been the standard treatment for AAA. However, it is classified as a high-risk surgery. The operation often takes a long time and patients typically lose a large amount of blood and the aorta is clamped for an extended period of time (Kristensen et al., 2014) . The surgery is performed under general anaesthesia. The abdomen is opened via a midline laparotomy and the aneurysm is repaired by opening the aneurysm sack and suturing a straight or bifurcated graft within it (El-Sabrout & Reul, 2001).

Endovascular treatment

The first EVAR was performed by a Ukrainian surgeon in 1987. This technique was introduced by the work of Parodi et al. (1991) and has since expanded to become a common operative technique in many vascular clinics (Greenhalgh, 2004; Patel et al., 2016). EVAR is classified as an intermediate risk surgery since it is less invasive than open surgery (Kristensen et al., 2014). Access to the aorta is commonly through the femoral artery, while the stent-graft is positioned under angiography (Seldinger, 1953). The treatment can be performed under local anaesthesia (Kristensen et al., 2014).

In randomised control trials (RCT), EVAR has been compared to open surgery and was shown to reduce short-term mortality and morbidity (Greenhalgh, 2004; Lederle et al., 2009). Recent research has also shown that elective EVAR in asymptomatic AAA with a single stent graft is even sustainable at long-term follow-up, especially for patients with suitable aortic anatomy for EVAR (Abdulrasak et al., 2020). The 30-day mortality rate for elective surgery is around 1 % among EVAR patients and around 4-5 % among open surgery patients (Wanhainen et al., 2019). Other advantages with EVAR include reduced blood loss and transfusion, mechanical ventilation, general anaesthesia and time spent in the intensive care unit as well as shorter hospital stay when compared to those undergoing open surgery (Kristensen et al., 2014; Wanhainen et al., 2019). The average in-hospital stay is 4 days after an EVAR and 11 days after open surgery for AAA (Greenhalgh, 2010). According to an annual report from the Swedish National Vascular Registry (2019), approximately 20% of patients that underwent open surgery had some form of early postoperative complication that was often related to the respiratory or cardiovascular systems (Swedvasc, 2019). For patients undergoing EVAR, there is a risk of developing an endoleak, which implies that the EVAR graft did not exclude the aortic aneurysm and blood is circulating outside the stent-grafts, thereby leading to renewed aneurysm growth. Notably, endoleaks increase the risk of reintervention. To monitor the risks of endoleak development, patients have been postoperatively followed via regular CT scans (Stather, Sidloff, et al., 2013).

Medical treatment

Unfortunately, there is no medical treatment available to stop AAA growth (Kokje et al., 2015). However, since patients with AAAs have a higher risk of cardiovascular morbidity and mortality, they are recommended to take medication to lower their blood pressure (if hypertension), statins and platelet inhibitors to prevent the atherosclerotic progression (Erbel et al., 2014; Wanhainen et al., 2019; Williams et al., 2018).

Smoking cessation and lifestyle changes

Since there is a strong correlation between smoking and developing AAA, AAA progression and risk for rupture (Kent et al., 2010; Sweeting et al., 2012), all patients should be advised to quit smoking (Grøndal et al., 2015). Notably, current smokers have an increased risk of AAA rupture.

Besides smoking cessation, healthy lifestyle changes should also be recommended for patients with AAAs and other cardiovascular diseases. These recommendations should include exercise (at least 30 minutes of moderate-intensity activity every day) (Eckel et al., 2014) and a well-balanced diet including vegetables, fruits, fish, poultry, vegetable oils and whole grains with a lower intake of sweets, sugar and red meat (Eckel et al., 2014; Kent et al., 2010).

1.2.5 Rupture of the AAA

The risk of aneurysm rupture increases with increasing aortic diameter. This is a major complication and common cause of sudden death among AAA patients (Sweeting et al., 2012; Wanhainen et al., 2019). The overall mortality rate for ruptures is between 50 and 80%, depending on timely arrival to a hospital. Among patients who reach a hospital alive, the mortality rate for emergency treatment is between 30 and 70% (Kniemeyer et al., 2000; Wilmink, Quick, Hubbard, et al., 1999). Thereafter, the 30-day mortality rate after emergency surgery varies; however, seen in a meta-analysis the 30-day mortality rate for patients treated with EVAR was 31.3% and 34% for open surgery (Sweeting et al., 2015). Ruptures before the age of 55 are uncommon with AAA diameters of less than 55 mm. Notably, the risk of rupture increases by 1 to 11% with an aneurysm diameter of 50 to 59 mm. Therefore, AAAs wider than 55 mm in males are recommended for elective treatment (Wanhainen et al., 2019).

1.3 Screening

The World Health Organization (WHO) has defined screening as “the presumptive identification of unrecognised disease in an apparently healthy, asymptomatic population by means of tests, examinations or other procedures that can be applied rapidly and easy the target population. A screening programme must include all the core components in the screening process from inviting the target population to accessing effective treatment for individuals diagnosed with the disease” (WHO, 2000).

The history of medical screening started with screening for syphilis and tuberculosis at the beginning of the 20th century. Medical screening aimed to cure patient and reduce the incidence of disease in the general population. One of the oldest screening programmes is the screening for psychiatric disorders in the United States army. The blood and urine glucose test for diabetes has been used in mass screening since 1940 and is one of the first modern forms of screening. During the last 30 years, screening programmes, especially for cancer, have increased, particularly in industrialised countries. Compared to infectious disease screening, this type of screening mainly reduces the mortality rate and does not lower the incidence of cancer in the general population (Morabia & Zhang, 2004). The general purpose of population-based screening is to detect diseases at an early asymptomatic stage and is routine in the health care (Holland & Stewart, 1990). Today, the wide range of existing disease screening programmes must meet the criteria for adequate screening outlined by the WHO. Wilson and Jungner (1968, pp. 26-27) presented the following criteria:

1. The condition sought should be an important health problem.
2. There should be an accepted treatment for patients with a recognised disease.
3. Facilities for diagnosis and treatment should be available.
4. There should be a recognised latent or early symptomatic stage.
5. There should be a suitable test for examination.
6. The test should be acceptable to the population.
7. The natural history of the condition, including development from latent to declared disease, should be adequately understood.
8. There should be an agreed policy on whom to treat as patients.
9. The cost of case-finding (including the diagnosis and treatment of diagnosed patients) should be economically balanced in relation to possible expenditure on medical care as a whole.
10. Case-finding should be a continuing process and not a “once and for all” project.

1.3.1 Screening for AAA

Screening programmes for AAA have been introduced in several countries based on the results of four RCTs (Ashton et al., 2002; Lindholt et al., 2002; Norman et al., 2004; Scott et al., 1995). A Cochrane review concluded that a significant reduction in AAA-related mortality rate was achieved in a cost-effective manner (Cosford & Leng, 2007). In a 13-year follow-up study, the rate of emergency operations for AAA was halved for men in the screening group when compared to the control group (Thompson et al., 2012). While international and national variations exist between screening programmes, all programmes offer an examination of the aorta with U/S

(Stather, Dattani, et al., 2013). In Sweden, all 65-year-old men are invited for a screening of the aorta. Any detected aneurysms wider than 30 mm will be followed up with regular U/S examinations. The frequency of surveillance depends on the size of the aneurysm. According to the European Society for Vascular Surgery guidelines, patients with an aneurysm of 50 to 55 mm width will undergo surveillance every 3 to 6 months (Wanhainen et al., 2019).

All screening programmes are associated with benefits as well as negative side effects. Over-diagnosis is reported as an important side effect in many types of screening (Welch et al., 2011). This is associated with stress and anxiety over possible diagnosis as well as concerns over false positive or negative results (Wardle et al., 1999). Emotional stress in conjunction with screening demonstrates that people cannot make informed choices regarding different treatments options and avoid follow-ups due to distress (Kash et al., 1992; Lerman & Schwartz, 1993).

In terms of AAA screening, the complete concept of overdiagnosis remains unclear. However, men often receive the clinical diagnosis and need to live with it, without having any use for the knowledge related to their AAA diagnosis (Moynihan et al., 2012). Johansson et al. (2015) estimated that 176 out of 10,000 men invited for AAA screening were over-diagnosed. While detection would not directly cause any symptoms or death, there is an estimated risk that 1 in 10,000 men attending AAA screening obtain a diagnosis, undergo an operation and die due to complications (Brownsword & Earnshaw, 2010). It may also be ethically controversial to search for disease in an asymptomatic population (SBU, 2008). Therefore, all screening programmes must be designed to meet fundamental ethical principles such as dignity and integrity (Wilson & Jungner, 1968). Another type of side effect is impacts on participants' QOL and well-being. For men with small aneurysms of ≤ 55 mm who were treated conservatively with continuous follow-ups, their awareness of the diagnosis may be controversial and mentally burdensome. Whether the awareness of having an AAA detected through screening and attending regular follow-ups influences individuals' well-being has been often been evaluated through the concept of QOL. Therefore, the literature review chapter (chapter two) will review and summarise evidence regarding QOL impacts among men that participated in AAA screening programmes. Furthermore, the literature review chapter (chapter two) will also synthesise these men's experiences of living with an awareness of their AAA. Living with the knowledge of having a potentially life-threatening diagnosis may not only affect the life situations of patients. Therefore, evidence focusing on the experiences and QOL impacts of partners living with men who have screening-detected AAAs and are under surveillance will also be summarised in the literature review chapter (chapter two). Moreover, the results of a literature search for health care professionals' experiences with caring for participants attending screenings will be provided.

1.4 Overall aim of the thesis

The overall aim of the thesis was to explore, describe and compare experiences and perspectives of screening-detected AAAs in a Swedish AAA screening context from the perspective of the affected men, their partners and health care professionals.

1.5 Working definitions

Several concepts were used in this thesis. This section presents working definitions for certain terms to outline the context of this thesis.

Partners

Partners are individuals defined as having a partner relationship, which is conceptualised as a romantic notion manifested through cohabitation or marriage (Hendrick & Hendrick, 2006).

Participants

The word “participants” is used when describing both the men with screening-detected AAA and their partners.

Health care professionals

In this study, the term “health care professionals” refers to registered nurses and medical doctors working within the AAA screening service. These individuals take care of the men that come coming for screening examinations and are under surveillance with regular follow-ups.

Screening

The word “screening” is used with different meanings in the literature, where it can imply a screening examination with a U/S of the aorta as well as being under surveillance. A person being under surveillance also implies that they attended a screening programme. However, “screening” refers to the screening examination itself in this thesis.

1.6 Organisation of the thesis

The present thesis is organised into six chapters. Chapter One presents the background of AAA diagnosis and the medical screening provided to detect AAAs among men above 65 years of age. The advantages of screening, as well as the harm screening can bring, are described. Such harm is further evaluated in Chapter Two, where the impacts on men's QOL are evaluated in the literature (also including a published narrative review). The men's general and broad experiences are also described in this chapter. The literature review also highlights research gaps within this area and establishes the purpose of the thesis. Living with an awareness of a potentially life-threatening disease does not only affect the patients themselves. Thus, evidence regarding impacts on partners living with men who have a screening-detected AAA is also summarised and described in Chapter Two.

Chapter Three presents the methodology used in the thesis. It clarifies the use of a single case study with the embedded units. The context of the case and the study population are also presented. Furthermore, this chapter describes the data collection and analysis methods. The central term of reflexivity and strategies for handling pre-understanding are also discussed. Furthermore, this chapter describes the ethical considerations of the present study.

Chapter Four presents the findings of analysing the three embedded units as well as their cross-analysis. This chapter is divided into four subsections. The first three subsections illustrate the perspectives and experiences of the partners (which also is a published qualitative descriptive study), men and health care professionals, respectively. The final subsection presents the cross-analysis, which also includes the health care professionals’ perspectives regarding caring for men with an AAA and their partners.

Chapter Five discusses the study findings that align with the relevant literature and theories. Components in the results are linked with the middle-range nursing theory of uncertainty in illness. The general limitations of the case study method are also presented alongside the limitations encountered throughout the research process, which should be considered when interpreting the results of this study.

The final chapter draws conclusions, provides recommendations and highlights clinical implications for future practice and care for the participants. Topics for future research that require further evaluation are also recommended in this chapter.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction to the literature review chapter

While screening for AAA is beneficial, it can also be related to harm and negative impacts on participants' lives. To evaluate the impacts of screening on patients' lives and well-being, quality of life (QOL) has commonly been used as an outcome. Therefore, this chapter provides details on a systematic search of the relevant literature on this topic as well as a literature review that summarises existing evidence regarding QOL impacts for men undergoing AAA screening who are under surveillance due to an AAA diagnosis. Studies that explored patients' experiences of screening-detected AAA diagnosis from a qualitative research perspective will also be highlighted in this chapter.

Since AAAs primarily affect men, screening is largely provided for this gender. However, awareness of a life-threatening diagnosis may affect individuals living with a diagnosed person. This is also a research topic that the Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU, 2008) proposes to develop and evaluate. Therefore, one subsection of this chapter will present the search for relevant literature in this area and provide general insights into how partners' lives can be affected by living with a person diagnosed with severe disease.

The literature review chapter is mainly divided into two subsections: one including the QOL impacts and experiences of diagnosed men and another including those of their partners. Each subsection will describe the search strategies, data extraction and synthesis followed by a summary of the evaluated studies. Furthermore, a brief subsection will outline the search for literature regarding health care professionals' experiences in caring for AAA patients. A summary of the subsections will be provided at the end of the chapter, which outlines the aim of the thesis.

2.2 Quality of life

Aorta screening and the detection of AAA makes participants aware of their diagnosis, which may impact their life situations and well-being. Since most AAAs are asymptomatic until rupture, it has previously been concluded that a greater focus should be placed on the psychosocial aspect of well-being (Cosford & Leng, 2007). However, most studies conducted within this research area have used general QOL instruments covering impacts on both physical and psychological well-being. This explains why the concept of QOL is used when focusing on the impacts on men's and their partners' lives in the literature review chapter.

A positive result from a screening test may result in negative feelings for participants, which can affect their lives. The concept of QOL is multidimensional and has been characterised in many different ways. It has also been used to describe items such as health status, well-being, satisfaction and happiness. According to Ventegodt et al. (2003), a high QOL implies a good life, while a good life is the same as living a life of high quality. Ventegodt et al. (2003) divided QOL into three aspects, each concerned with an aspect of having a good life. The first aspect is subjective QOL, which pertains to how good a life each individual feels they have. It also evaluates how they view things as well as their feelings and notions. The second aspect is existential QOL, which refers to how good one's life is at a deeper level. The third aspect is objective QOL, which focuses on how one's life is perceived by the outside world. This view is influenced by the culture in which people live and their ability to adapt to the values of a culture (Guyatt et al., 1993). The WHO definition for QOL was used when reviewing the literature, which is "the individuals' perception of their position in life in the context of the culture and value system and in relation to their goals, expectations, standards and concerns. It incorporates in a complex way individuals' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment" (WHO QOL GROUP, 1995, p. 1405).

The objectives of the literature review were to review and summarise evidence regarding men’s QOL impacts and experiences of living with a screening-detected AAA. Furthermore, literature regarding partners’ experiences and the QOL impacts of living with a man that has a screening-detected AAA was reviewed. Lastly, health care professionals’ experiences of taking care of men under screening surveillance and their family members were reviewed.

2.3 Method for the review

2.3.1 Search strategy

The literature was searched in three different databases—PubMed, MEDLINE (1965+), Cumulative Index to Nursing and Allied Health Literature (CINAHL

1982+) and PsycINFO (1806+)—and adjusted search strategies were used in the chosen databases. To combine different search terms, the Boolean search operators OR and AND were used. The main literature search was performed from April to July 2016, with updated searches performed from February to March 2018 and in August 2020. The search terms included a combination of free text and subject heading terms. The initial keywords were abdominal aortic aneurysm, aortic screening/mass screening/screening programme and QOL/psychosocial consequences/anxiety/depression/mental stress/effects on daily life/well-being/experiences. Additionally, the reference lists of retrieved studies were screened for relevant studies. There were no language restrictions or limitations on publication dates.

To assess the evidence regarding QOL impact in men undergoing screening, peer-reviewed quantitative, mixed-method and qualitative studies were included with a focus on the impact of QOL in men undergoing AAA screening. The inclusion criteria for study outcomes included men's perceptions of QOL concerning one or more of the following concepts: physical function, psychological impact, social life and experiences of living with the knowledge of having the diagnosis. Studies that explored only one aspect of the QOL concept were also included. Studies that presented impacts on the QOL of participants diagnosed with an AAA but did not involve them attending a screening programme were excluded.

Initially, the results of the search (n=531) were merged into the reference management software EndNote (X8). Duplicates were removed (n=349). A manual review of the remaining 182 titles and abstracts resulted in 68 articles being excluded. Subsequently, 33 full-text articles were reviewed, of which 19 were excluded based on the inclusion and exclusion criteria (Figure 2).

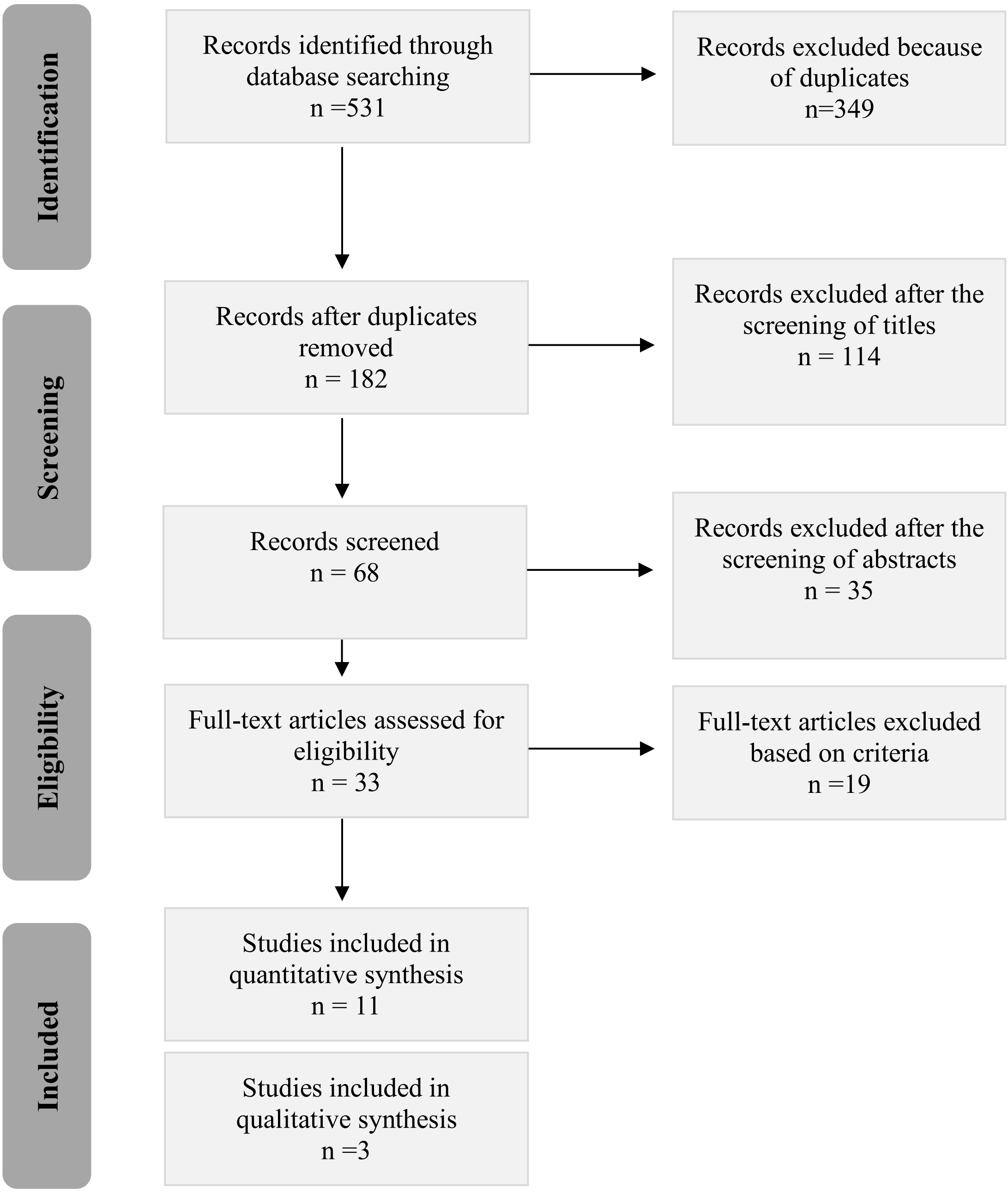

Figure 2 Flow diagram of identified, screened and included studies.

2.3.2 Data extraction and study quality appraisal

For the included quantitative studies, the following data were extracted: 1) author, year of publication and country of origin, 2) subjects and sample size, 3) study design, 4) instruments, 5) time for assessment and follow-up, 6) outcomes and 7) quality appraisal. For qualitative studies, the following data were extracted: 1) author, year of publication and country of origin, 2) participants and setting, 3) method and analysis, 4) results and 5) quality appraisal.

To assess the quality of the included qualitative, observational and RCT studies, respective checklists from the Critical Appraisal Skills Programme (CASP) were used. These consist of 10 to 12 questions that aim to evaluate the validity and generalisation of results (CASP, 2014). The PhD candidate assessed the quality of studies with her supervisors, compared the scores, discussed any discrepancies and agreed on a final score. The agreements between the authors were good overall. Since the PhD candidate and one of her supervisors are authors of one of the included studies (Ericsson et al., 2017), two external reviewers were invited to assess the quality of this study. The response options in the checklists were “Yes”, “No” or “Can't tell”. "Can't tell" responses were counted as a "No". Based on the number of "Yes" responses in the checklists, total scores below 50% indicated poor study quality, while scores between 50 and 75% indicated fair quality and scores above 75% indicated high-quality studies. Three of the studies were of high quality, while seven were of fair quality and one was of poor quality.

2.3.3 Synthesis

An integrative approach was used in the review, while the qualitative and quantitative syntheses were conducted in parallel and are reported separately (Pearson et al., 2014).

The data extracted from quantitative studies were summarised. A narrative synthesis provided a detailed description and a summary highlighting the similarities and differences of the content of included quantitative studies. The narrative descriptions were reported as "Comparisons between the included samples and changes within the included samples" (Cronin et al., 2008).

The data extracted from qualitative studies compared the different levels of analysis in an attempt to transform the information from the studies into one another, with inspiration from Noblit and Hare (1988) meta-ethnography version. The first step in the process involved reading and identifying the PhD candidate's view and interpretation of the original studies. Keywords and themes were extracted and noted in an attempt to determine how the studies were related to each other (Malpass et al., 2009). The keywords and themes were then placed together in a grid. By comparing differences and similarities between these themes and keywords, new categories were created. Upon describing the content of qualitative studies, a trend of changes in participants' feelings and experiences over time was shown.

2.4 Results of the reviewed studies

The results section is divided into two subsections: one focused on quantitative studies and another focused on qualitative studies.

2.4.1 Quantitative results

The review chapter includes 11 quantitative studies. Although one of the studies had a mixed-method design, the quantitative portion was appropriate to the objective of this review and was thus included in the review.

2.4.1.1 Description of the studies and subjects

All of the included studies evaluated the QOL impacts for men with screening-detected AAA and were conducted between 1997 and 2018. The majority of the studies originated from Europe, including five from the United Kingdom (Ashton et al., 2002; Bath et al., 2018; Khaira et al., 1998; Lucarotti et al., 1997; Marteau et al., 2004), three from Sweden (Ericsson et al., 2017; Pettersson et al., 2014; Wanhainen et al., 2004), one from Denmark (Lindholt et al., 2000) and two from Australia (Lesjak et al., 2012; Spencer et al., 2004).

A total of 2,800 subjects were diagnosed with an AAA via the U/S technique and their ages ranged from 65 to 83 years old. The study samples varied from 86 subjects to a large population-based RCT with 27,147 subjects. A small sample of women (4 in the AAA group and 10 in the control group) was included in one of the studies and grouped with the male subjects (Wanhainen et al., 2004). While questionnaires were sent to the partners of the men included in one study (Spencer et al., 2004), only findings from men with AAAs were included in this review chapter.

Different designs were reported among the studies. However, the majority were observational studies. Overall, five were prospective studies (Bath et al., 2018; Ericsson et al., 2017; Lesjak et al., 2012; Marteau et al., 2004; Wanhainen et al., 2004), two were case-control studies (Lindholt et al., 2000; Lucarotti et al., 1997), one was a combination of cross-sectional and case-control (Spencer et al., 2004) and one was an RCT (Ashton et al., 2002). Moreover, the quantitative portion of the study using mixed methods (Pettersson et al., 2014) had a cross-sectional design. One of the studies did not mention a design but was followed up as a prospective case-control study (Khaira et al., 1998). In the case-control studies, the subjects diagnosed with an AAA were compared to matched controls who were not diagnosed with an AAA at the screening examination (Lindholt et al., 2000; Lucarotti et al., 1997; Spencer et al., 2004), the Swedish SF-36 normative general population data (Wanhainen et al., 2004), patients from a waiting list for AAA surgery not diagnosed through screening (Khaira et al., 1998), subjects not randomised for screening (Lindholt et al., 2000) and men who underwent surgery for AAA (Ashton et al., 2002; Lindholt et al., 2000). In one study (Lindholt et al., 2000), the AAA sample was compared to men who refused an invitation for screening. In the study by Pettersson et al. (2014), the entire screening sample (men with AAAs and those without) was compared to an age- and sex-matched control group from the national general population normative database with regards to SF-36. For the prospective studies, all participants with an AAA were followed up and compared to randomised groups without an AAA (Bath et al., 2018; Ericsson et al., 2017; Lesjak et al., 2012; Wanhainen et al., 2004). In the study conducted by Marteau et al. (2004), only a subsample of both groups was followed up.

2.4.1.2 Assessment time

The time for assessing QOL in the reviewed studies varied (Table 1). In total, 7 of the 11 studies had baseline information measured in conjunction with screening (Bath et al., 2018; Lesjak et al., 2012; Lindholt et al., 2000; Lucarotti et al., 1997; Marteau et al., 2004; Spencer et al., 2004; Wanhainen et al., 2004). The first assessments of the participants in the remaining four studies were 1 to 2 weeks (Pettersson et al., 2014), 4 weeks (Khaira et al., 1998), 6 weeks (Ashton et al., 2002) and up to 12 weeks (Ericsson et al., 2017) after the initial screening. The majority of the studies were prospective and the follow-up assessments ranged from 1 month up to 4 years. Two of the studies (Ashton et al., 2002; Lindholt et al., 2000) compared subjects under conservative treatment attending follow-ups with those who underwent surgery. These studies followed the patients for up to 1 year after surgery.

Table 1 Time period for QOL assessment and follow-ups.

	Before screening	**1–2 weeks after screening**	**4–6 weeks after screening**	**12 weeks after screening**	**4–6 weeks after screening**	**3 months after screening**	**6 months after screening**	**12 months after screening**	**Annual/after surgery**
Lucarotti	⦸				⊙				
Khaira			⦸		⊙		⊙		
Lindholt	⦸				⊙				⊙
Ashton			⦸		⊙	⊙		⊙	⊙
Spencer	⦸							⊙	
Wanhainen	⦸							⊙	
Marteau	⦸				⊙				
Lesjak	⦸						⊙		
Pettersson		⦸							
Ericsson				⦸			⊙*		
Bath	⦸+							⊙	⊙#

⦸ = First assessment

⊙ = Follow-up

+ = At the initial screening appointment

* = 6 months after the first assessment

= Annually for up to 4 years

2.4.1.3 Quality of life instruments

To assess whether the screening for AAA had an impact on QOL, different QOL instruments were used in the included studies. However, the majority were generic instruments and often used in combination with each other. The most frequently used generic instrument was the MOS 36-Item Short Form Health Survey (SF-36), which was observed in eight of the studies (Ashton et al., 2002; Bath et al., 2018; Ericsson et al., 2017; Lesjak et al., 2012; Marteau et al., 2004; Pettersson et al., 2014; Spencer et al., 2004; Wanhainen et al., 2004). Based on this instrument, Marteau et al. (2004) and Spencer et al. (2004) included five questions under the dimension of general health perception. The study by Spencer et al. (2004) used the entire SF-36 scale at the follow-up assessment. SF-8 (the short form of SF-36) was used in the study by Bath et al. (2018). Furthermore, the standardised generic EuroQoL (EQ-5D) instrument was used in two of the reviewed studies (Ashton et al., 2002; Spencer et al., 2004) to assess physical, social and mental health. To capture psychological well-being that may have an impact on the QOL, other generic instruments were used. The Hospital Anxiety and Depression Scale (HADS) was utilised in six of the reviewed studies (Ashton et al., 2002; Ericsson et al., 2017; Khaira et al., 1998; Lesjak et al., 2012; Pettersson et al., 2014; Spencer et al., 2004) to assess states of depression and anxiety. Anxiety was also assessed using the Spielberger State-Trait Anxiety Inventory (STAI) in combination with other instruments in one study (Ashton et al., 2002). To identify minor psychiatric disorders in a general population, the General Health Questionnaire (GHQ) was an alternative tool used by Lucarotti et al. (1997). To report the psychological consequences of screening, the validated Screen Quality of Life Questionnaire (ScreenQL) was used in one Danish study (Lindholt et al., 2000). Single instruments were also used in some of the studies. Ten non-validated AAA-specific questions were used in the studies by Wanhainen et al. (2004) and Ericsson et al. (2017). The study by Lucarotti et al. (1997) added a linear analogue scale to measure anxiety. Bath et al. (2018) used a Likert scale to ask how often the subjects thought about their aneurysm, while Spencer et al. (2004) used a few stand-alone questions about QOL from two validated instruments, the STAI and the Life Orientation Test.

2.4.1.4 Relationship between AAA screening and QOL

Comparison between groups

Self-assessed health from the dimension of general health perception (SF-36) indicated lower scores before U/S examinations among men for which an AAA was later detected when compared to participants not diagnosed with an AAA (Marteau et al., 2004; Spencer et al., 2004; Wanhainen et al., 2004). Psychological and physical health (reported as PCS, MCS and General Health) was reported as lower in the group diagnosed with an AAA than in those without the diagnosis 6 weeks after the screening examination (Ashton et al., 2002; Marteau et al., 2004). Physical health was reported to be significantly lower 6 months after the first QOL assessment Ericsson et al. (2017) (reported as physical function and physical role limitation), even lower 12 months after the screening examination (Spencer et al., 2004) (reported as physical function and physical role limitation) and lower again after a period of 3 years when compared to those without an AAA diagnosis (Bath et al., 2018) (reported as PCS). Psychological health was significantly lower for men with the diagnosis within the first year after the screening examination when compared to men without an AAA (Bath et al., 2018) (reported as MCS). Lesjak et al. (2012) found that the men with an AAA reported significantly lower scores in the dimensions of social functioning, pain and general health 6 months after the U/S examination when compared to men without the diagnosis. A significantly higher level of stress in relation to disease was observed 6 months after the first QOL assessment in Ericsson et al. (2017) for men with an AAA compared to those without, which is illustrated in Table 2.

Table 2 Differences in QOL for studies that included comparative groups at the follow-up assessment between participants with and without an AAA. The included studies have different times for follow-up.

Instrument	**Lucarotti**	**Khaira**	**Lindholt**	**Ashton**	**Marteau**	**Lesjak**	**Wanhainen**	**Spencer**	**Ericsson**	**Bath**
SF-36							=			
Physical function							=	↓*	↓*	
Physical role limitation						=	=	↓	↓*	
Pain						↓*	=		↓	
General health					↓	↓*	=		↓	
Vitality							=	↓	↓	
Social functioning						↓*	=		=	
Emotional role limitation							=		=	
General mental health							=		↓	
PCS				↓*			=		↓	↓*
MCS				↓*			=		↓	↓*+
HADS		=		=		=		=	=	
GHQ	=									
Screen QL										
Health			↓*							
Quality of life			↓*							
EQ-5D				↓				=		
Stress due to disease									↓*	
Sense of coherence									=	

* = Reported as significant in the original studies
= No differences reported
\+ Reported as a significant reduction the first year after screening
↑ = Better reported health status
↓ = Worse reported health status
EQ-5D = EuroQoL 5 Dimensions
GHQ = General Health Questionnaire
HADS = The Hospital Anxiety and Depression Scale
MCS = Mental Component Score
PCS = Physical Component Score
Screen QL = Screen Quality of Life Questionnaire
SF-36 = Short Form 36 Health Survey

Comparison with the general population

Both men with and without AAA attending screening reported significantly better psychological and physical health 7 to 14 days after the screening examination when compared to the SF-36 standard values of an age- and sex-matched Swedish population (Pettersson et al., 2014). However, comparisons of the norms of the general Swedish SF-36 population and the AAA group indicated a significantly lower psychological and physical health status for the AAA group 12 months after the first screening examination (Wanhainen et al., 2004).

Changes within the groups

Significantly lower anxiety levels were noted 4 weeks after the screening examination for men diagnosed and not diagnosed with an AAA at screening appointments (Lucarotti et al., 1997). Marteau et al. (2004) noted that the men with AAAs continued to report decreasing self-perceived general health 6 weeks after the screening examination when compared to before the examination. A decreasing trend in psychological and physical health was shown among men with an AAA over time (Lindholt et al., 2000; Wanhainen et al., 2004). Moreover, Wanhainen et al. (2004) reported decreased social functioning scores after 12 months, while Ericsson et al. (2017) noted decreasing emotional role functioning scores for men with an AAA 6 months after screening. Two studies (Ashton et al., 2002; Lindholt et al., 2000) showed that the impairment of psychological and physical health continued further until after surgery. The changes in QOL for men with an AAA are presented in Table 3.

Table 3 Differences in QOL within the AAA group for studies that followed participants over time.

Instrument	**Lucarotti**	**Khaira**	**Lindholt**	**Ashton**	**Marteau**	**Lesjak**	**Wanhainen**	**Spencer**	**Ericsson**
SF-36									
Physical function						↑	↓*		↓
Physical role limitation						↓	↓		↓*
Pain						↓	↑		↓
General health					↓	↑	↓	↑	↓
Vitality						↓	↓		↓
Social functioning						↓	↓*		=
Emotional role limitation						↓	=		↓*
General mental health						=	↓*		↑
PCS				↑			--		↓
MCS				↑			↓*		↓
HADS		=				=			=
GHQ	↓*!								
Screen QL									
Health			↓*						
Quality of life			↓*						
Emotional			↓						
Psychosomatic distress			↓						
EQ-5D				↑					
State anxiety				↓					
Stress due to disease									=

GHQ: Reduction in anxiety level = better status
Screen QL: Lower psychosomatic stress = worse status
= No difference
↑ = Better health status
↓ = Worse health status
* = Reported as significant in the original studies
EQ-5D=EuroQoL 5 Dimensions
GHQ=General Health Questionnaire
HADS= The Hospital Anxiety and Depression Scale
MCS= Mental Component Score
PCS=Physical Component Score
Screen QL = Screen Quality of life Questionnaire
SF-36= Short Form 36 Health Survey

2.4.1.5 Methodological aspects of the included quantitative studies

There was wide variation in the quality of the included studies due to different methodological issues. None of the included studies achieved highest possible score in the quality appraisal based on the CASP appraisal. The majority of the studies presented clear objectives (except one (Khaira et al., 1998)) and the designs of the studies were stated. For the case-control studies, matched controls were recruited after the screening examination, where subsamples of the men without an AAA diagnosis became controls. This led to an assessment of the studies considered to be the exposure to determine whether the authors aimed to evaluate the associations between screening and QOL or between AAA diagnosis and QOL. It can be assumed that the authors of the studies considered the assessments to be rather similar or that they aimed to evaluate the awareness of the diagnosis and followed up through screening. While the sample sizes and dropout rates were described in all of the studies, it can be questioned whether the numbers of cases were sufficient since only one study reported a sample size calculation (Ashton et al., 2002). Furthermore, only two studies stated how they handled the dropout rates and incomplete questionnaires in their analyses (Khaira et al., 1998; Spencer et al., 2004). Confounders were considered in 3 of the 11 studies (Bath et al., 2018; Ericsson et al., 2017; Lindholt et al., 2000), which should be considered a limitation since patients with AAAs generally have more comorbidities. Most of the QOL instruments used in the studies were validated instruments and were adequately described in all of the studies. However, while Lindholt et al. (2000) stated that ScreenQL was validated and sensitive for the population, this was difficult to verify since a citation was not included and searches could not identify this tool. This study, Lindholt et al. (2000) further aimed to measure the psychological consequences of screening; however, the instrument used covered health in general—an issue similar to that of other studies. Furthermore, Lucarotti et al. (1997) aimed to measure psychological morbidity but mostly focused on the concept of anxiety. Since most of the instruments in the included studies were generic, it can be questioned whether they were the most appropriate for evaluating QOL among patients with screening-detected AAA. Although SF-36 has been proven as the most valid and reliable instrument to measure QOL in patients with vascular disease (Beattie et al., 1997), generic instruments are often used in a general population without any particular disease and SF-36 has previously been criticised for being too general in screening programmes for breast cancer (Rijnsburger et al., 2004). It appeared that more emphasis was placed on the physical QOL impact among men with AAAs. This might reflect outcomes unrelated to the AAA diagnosis since the majority of AAAs are asymptomatic (Vardulaki et al., 1999). However, screening makes participants aware of the diagnosis. According to a previous Cochrane review (Cosford & Leng, 2007), the focus of future research should be the psychosocial aspect of one's well-being. Nevertheless, a non-validated instrument was used in combination with other instruments in two of the studies constructed for a specific population that focused on the information and screening process (Ericsson et al., 2017; Wanhainen et al., 2004). Notably, the definitions of what the original studies aimed to measure were generally not presented. A similar case was noticed in the cancer screening literature, where it was concluded that emotional terminology is difficult to define (Vardulaki et al., 1999).

2.4.2 Qualitative results

This subsection presents the result of the qualitative studies with a focus on the men's experiences with screening-detected AAA.

2.4.2.1 Descriptions of the qualitative studies and the participants

Notably, all of the qualitative studies were conducted in Sweden (Berterö et al., 2010; Brännström et al., 2009; Hansson et al., 2012). A total of 28 men diagnosed with an AAA via screening were interviewed in these three studies. Two of the studies used semi-structured interviews following an interview guide (Berterö et al., 2010; Hansson et al., 2012). Men from one of the studies (Wanhainen et al., 2004) were recruited because of their low SF-36 scores after AAA screening and were followed up with interviews 5 years after their screening examination. Two-thirds of the participants had undergone surgery for AAAs when their interviews took place (Brännström et al., 2009). Interviews for the other two studies took place 2 to 4 months after screening (Hansson et al., 2012) and within the first year after examination (Berterö et al., 2010). A descriptive summary of the qualitative studies is presented in Table 4.

2.4.2.2 Methodological aspects of the included qualitative studies

The methodologies of the qualitative studies were based on the CASP qualitative appraisal tool. The aims were stated for all three studies and the interviews were appropriate for the research questions. In one of the studies, the aim stated in the abstract differed from the aim presented the main body of the paper (Berterö et al., 2010). Settings and participants were clearly described in all three studies. Moreover, the analyses were clearly described in all studies and the level of abstraction was also easy to follow in one of the studies (Hansson et al., 2012). All three studies used different analysis methods. While ethical approval was received for all three studies, it was not clearly stated whether signed consent forms were obtained from the patients. While none of the studies achieved fully quality scores, they were included in the review since they were judged to be key papers and relevant to the objective of this review.

2.4.2.3 Synthesis: The linkage between feelings and time after screening examination

Despite differences in the quality of methodologies, participants, time periods for interviews and analysis methods among the included qualitative studies, common experiences of undergoing screening for AAA were identified. Experiences and feelings that impacted participants' daily lives and QOL were described. In the synthesis, changes in participants' feelings and experiences over time can be discerned (Table 4).

Table 4 Synthesis of the qualitative studies, including the keywords and themes from the original studies and the newly created categories.

Categories	**An unexpected message**	**Feeling secure**	**To be aware and try to live as usual**	**Disappointment when expanding**	**A calmer opinion**
Berterö	Surprised, affected but manageable	To be under superintendence and actions were taken	Suppressed thoughts	Disillusionment and limited when expanding	
			Always in their back		
Hansson	Shocked and fear of death	Preventing early death	Live as normal with a range of coping strategies	Losing control Reminder of growing older	
	Catastrophe and disappointment		Support from relatives	Ambivalence about knowing	
Brännström		Involved in decision making Having a relationship and the ability to help			Silent condition, neither harm nor good Like a drop in the ocean

Timeline→--------------Screening--------A more positive attitude----------------------A more negative attitude----5 years after screening

An unexpected message

Receiving messages about AAA diagnosis based on U/S examination was surreal, shocking and brought disappointment to many participants. However, some mentioned it as manageable. Negative thoughts and fear of death appeared from the time of the screening examination to the appointment with a medical doctor (Berterö et al., 2010; Hansson et al., 2012).

Feeling secure

In combination with the skills and competence of the health care system, the regular follow-ups and surveillance offered by the screening programmes resulted in positive attitudes and feelings of trust. To be involved in decision making resulted in an understanding of the process. The health care system provided conservative treatments for hypertonia and hyperlipidaemia and promoted lifestyle changes, which resulted in the adoption of healthier lifestyles by some participants. Opposing views regarding health factors and lifestyles with reactions stating that the health care system should not interfere were also described (Berterö et al., 2010; Brännström et al., 2009; Hansson et al., 2012).

To be aware and try to live as usual

Tolerance and acceptance of their conditions and circumstances became apparent as participants attempted to live their lives as normal and continue with physical and social activities. The participants were reminded of having the disease from time to time, especially during physical activities or when experiencing symptoms such as pain in the abdominal region. To maintain their daily lives and reconcile themselves with an awareness of the disease, a range of different coping strategies were mentioned. The importance of having support from relatives was also described as positive (Berterö et al., 2010; Hansson et al., 2012).

Disappointment when expanding

During the course of surveillance and especially if the AAA continued to expand, the participants sensed a loss of control over their health. Moreover, feelings of disappointment and fear were common. Fear of the future, the threat of uncertainty and anxiety related to either surgery or rupture were experienced. These feelings were so hard to bear that some participants described wishing that they did not know their diagnosis (Berterö et al., 2010; Hansson et al., 2012).

A calmer opinion

A calmer attitude five years after the screening was mentioned in Brännström et al. (2009). Some participants compared AAA to other illnesses and experienced it as a silent condition that did neither harm nor good. Even a burst and death from the aneurysm was described as a relief from other suffering by some participants.

2.5 Introduction to the subsection on partners

The diagnosis of a chronic life-threatening disease affects patients’ as well as their partners’ lives in different ways (Dalteg et al., 2011; Eriksson et al., 2019). Abdominal aortic aneurysm with rupture as the major consequence is a life-threatening disease that can affect an entire family. Therefore, screening programmes for AAA have been introduced in several countries to reduce the mortality rate. However, the awareness of having an AAA diagnosis influences individuals' QOL and well-being, as seen in the previous subsection of this chapter. However, this portion of the literature review chapter will focus on partners' experiences and well-being when living with a man that has a screening-detected AAA. Furthermore, it provides a general description of partners' experiences of living with people diagnosed with life-threatening diseases.

2.5.1 Literature search

The databases PubMed, CINAHL and PsycINFO were used for searching. The Boolean search operators OR and AND were used. Search terms and free text were combined in the searching process. The initial keywords were partners, spouses, informal caregivers, wives, abdominal aortic aneurysm, screening, QOL, experiences, well-being, burden and needs. All types of studies were included and there were no limitations on dates of publication. The search related to the partners was conducted from 01/04/17 with continues updates until 02/09/19.

2.5.2 Search outcome

The initial outcome of the search included 22 studies. All titles and abstracts were reviewed and two of them were reviewed in full-text. One study met the inclusion criteria describing partners' QOL (Figure 3). This study had the partners as a subpopulation to men with a screening-detected AAA and was thus included in the review of the men as well.

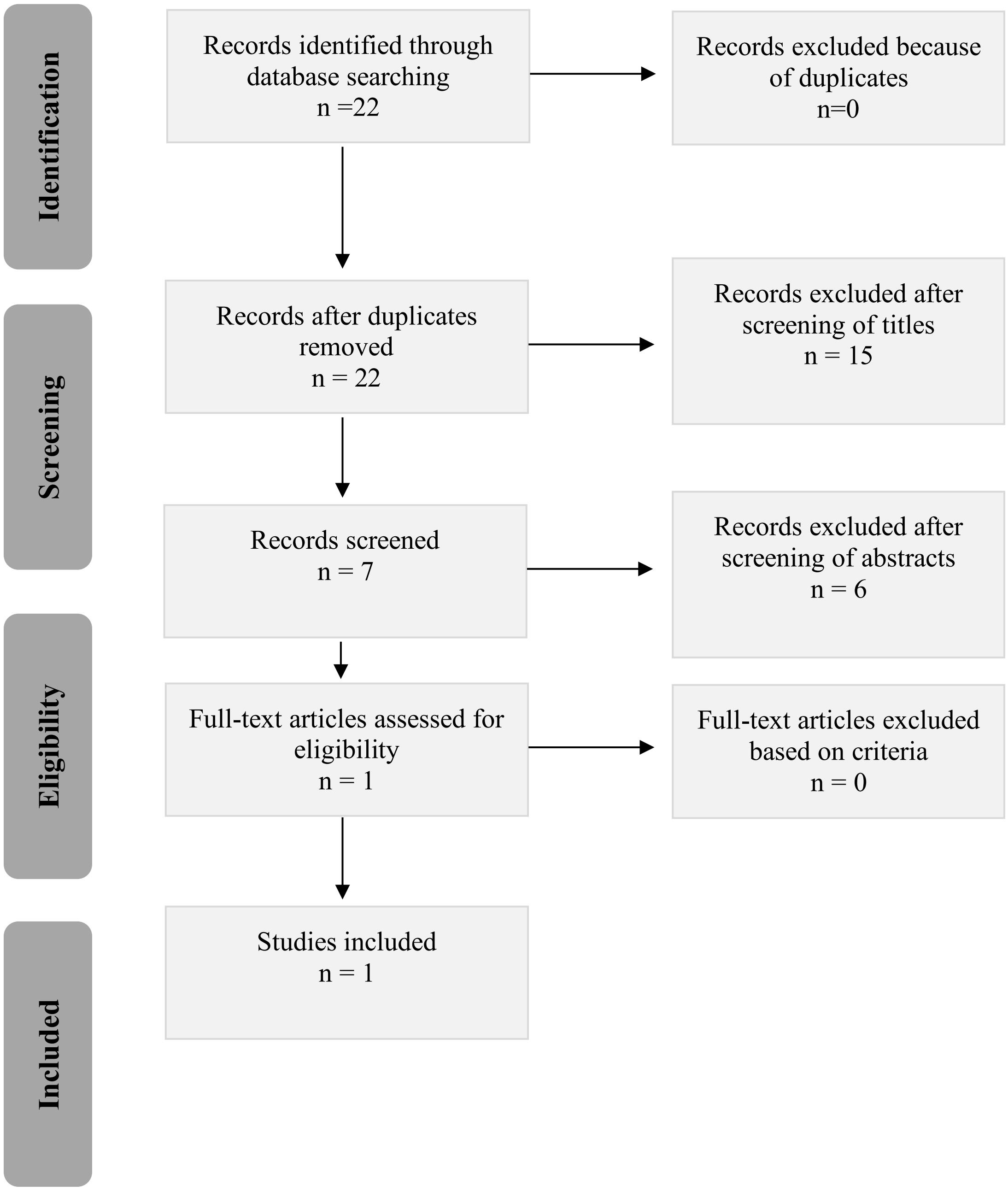

Figure 3 Flow diagram of identified, screened and included studies.

In 2004, the only study to evaluate partners' perceptions and QOL impacts was conducted in Australia. It was a cross-sectional design that assessed QOL 12 months after the initial screening. The instruments used were SF-36, HADS and EQ-5D. Eight questions from the STAI and Life Orientation Test were sent out to the partners of men, both with and without AAAs, who attended the screening. The study concluded that no significant differences were observed between the first group (i.e., partners of men with AAAs) and the second group (i.e., partners of men without AAAs) regarding either anxiety or QOL (Spencer et al., 2004).

2.5.3 Background on partners’ experiences with patients who have a severe diagnosis

Based on the search outcome, with only one study presenting partners’ QOL, a general descriptive background of how partners experience living with people who have a life-threatening disease (e.g., cardiovascular disease) will follow to provide an overall understanding of their experiences.

When people are diagnosed with chronic life-threatening diseases, both them and their partners are affected in different ways. Commonly, relationships are affected when the diagnosed individuals report feeling overprotected or experience communication deficiencies, sexual concerns and changed domestic roles (Dalteg et al., 2011). This can lead to a heavier workload for the partners than diagnosed individuals (Söderberg et al., 2003). In addition to the diagnosed persons, partners also report burdens and symptoms. This stems from worry about the person who was diagnosed as well as the consequences of the disease in their present and future lives. More specifically, the partners of people with chronic diseases have reported emotional distress, fear of the future, depression, anxiety, social disruptions and feelings of powerlessness (Öhman & Söderberg, 2004). Moreover, evidence has shown that the partners of individuals diagnosed with chronic life-threatening diseases may experience heavier burdens, particularly when their needs are ignored by themselves, their families and the health care system (Barker et al., 1990). The effects and problems that a partner must face depend on the disease that their ill partner suffers from. Furthermore, they can also depend on gender differences. For example, the female partners of acute myocardial infarction survivors experienced a range of distressing emotions while struggling to regain a sense of control over their lives (Öhman & Söderberg, 2004).

2.6 Health care professionals' perspectives

The databases PubMed and CINAHL were used for the literature search on health care professionals' perspectives regarding their experiences in caring for patients under AAA screening surveillance and their partners. The Boolean search operators OR and AND were used. Search terms and free text were combined in the search process. Initial keywords were health care professionals, providers, nurs* caregivers, experiences, views, perceptions, perspectives and AAA screening patients,men. Based on the search, no studies aimed at assessing health care professionals' perspectives on caring for AAA screening patients/men were found. However, their experiences with the care given to men under AAA screening surveillance and their perspectives on the participants' experiences can provide additional insight into health barriers and enablers in the AAA screening context. Therefore, an interview study with health care professionals was conducted for the present study.

2.7 Chapter summary and research gaps

Quality of life has been—and remains—an important outcome within the AAA research area since screening and being under surveillance reminds affected individuals about a potentially fatal disease. This aspect must be carefully weighed against the mortality rate in diagnosis and cost-effectiveness. A considerable number of studies have been conducted since the start of AAA screening to address QOL. However, it remains a challenge to conclude any imbalance between benefits and harm for participants living with an awareness of screening-detected AAAs. This might be due to the limited number and heterogeneity of the studies reviewed in this chapter.

Existing studies have reported both positive and negative QOL impacts for participants that attended a screening programme and were diagnosed with an AAA. However, as revealed in the literature, men with screening-detected AAAs exhibit a trend of decreased QOL and tend to have inferior QOL and health in comparison to those without an AAA diagnosis. The conclusion that this negative trend and poorer health depends on the awareness of screening-detected AAA alone is difficult to support since baseline information should have been assessed before inviting participants for a screening examination. However, this would have been difficult to implement. Furthermore, AAA patients often suffer from other cardiovascular diseases, which might have also resulted in decreased QOL. Furthermore, variation in methodological quality exists among the reviewed studies in terms of the sample size, research design and outcome measures used. This also makes it difficult to summarise the results from the original studies. Notably, improved methodologies would have made the conclusion more reliable.

Additionally, a possible pattern of change over time when the men are under surveillance could be discerned from both the qualitative and quantitative studies. Most impacts related to AAA diagnosis involving negative feelings were also expressed in the qualitative studies when patients’ AAAs continued to expand.

Since there is a lack of conclusive knowledge regarding QOL impacts, further studies of higher methodological quality are needed. Nonetheless, a review of findings from the literature indicated areas that can be improved to enhance care for these men. Additionally, the awareness of screening-detected AAA may affect the partners living with diagnosed men. However, only one of the included studies evaluated QOL impacts on partners from a quantitative perspective. Moreover, it remains unclear how these partners experience the situation of living with a man that has an AAA. Therefore, further research is required to gain a deeper understanding of the affected partners’ perspectives and experiences.

The detection of the AAA through screening prevents disease-related mortality. However, detection also results in more individuals having to face the negative side effects of living with an awareness of a potentially life-threatening disease. Since this issue is common among screening programmes, there exists a need for further exploration and description of participants' experiences to gain additional insights and knowledge regarding their life situation and enhance support for the participants. When conducting research, it is essential to meet a phenomenon from different perspectives, especially if it aims to facilitate the development of interventions within the same context (Craig et al., 2008). Studies have previously concluded that health care professionals working in AAA screening should be sensitive and available to meet patients’ individual needs for care and support (Ericsson et al., 2017; Pettersson et al., 2014). However, no studies have focused on health care professionals’ perspectives regarding their experiences in caring for men with screening-detected AAA and their families. Therefore, the views of health care professionals that work in AAA screening and care for the participants are meaningful. Their views and experiences can create a broader and deeper understanding of the care given to participants while also clarifying health care barriers for the affected men and their partners.

2.8 Aim and objectives of the thesis

This thesis aimed to explore, describe and contrast experiences and perspectives of screening-detected AAAs in a Swedish AAA screening context from the perspectives of affected men, their partners and health care professionals.

The objectives were:

- ⇒ To gain a deeper understanding and knowledge regarding men's and their partners' experiences of living with a screening-detected AAA.
- ⇒ To address health care professionals' views on caring for men with a screening-detected AAA and their partners and describe their perspectives on health care barriers and enablers in the AAA screening context.
- ⇒ To contrast experiences related to an AAA detected through screening and through the contrasts identify areas for improvement and to address unmet needs.

To meet the aforementioned aim and objectives, a qualitative case study design was used, which will be presented in the next chapter alongside the methods used for collecting and analysing the data.

CHAPTER THREE

METHODOLOGY

3.1 Introduction to the methodology chapter

According to the literature, there are knowledge gaps regarding men's and the partners' perspectives on living with screening-detected AAA and being under surveillance as well as health care professionals' perspectives on caring for them. To close these gaps and contrast the perspectives of these three groups, a qualitative single case study with embedded units was conducted. This chapter describes the research methodology, methods and analysis. Moreover, it also explains the main approaches taken to ensure the rigour of the present study. To meet the objectives of the study, data were collected through individual and focus groups interviews. These data were then analysed by qualitative content analysis (QCA) and moderated narrative approaches. A summary of the methodology is presented at the end of the chapter (3.8).

Paradigm is a fundamental approach in the process of conducting research and can be considered a "frame of beliefs." It is sometimes described as a "worldwide lens" of how one perceives reality and is constructed by communities that share values and beliefs about nature, existence and reality. Paradigm reflects on ontological, epistemological and methodological structures and directions and builds up methods to be used in research. This study falls under the paradigm of post-positivism (Kuhn, 1970).

3.2 Post-positivism

Philosophical frameworks, research traditions and paradigms are some of the terms used to describe worldviews that underpin the foundations of research. All of us have a worldview that impacts the way we think, what kind of assumptions we make, how we behave and how we organise our lives. Notably, our worldviews also influence our research approaches. Research works within a specific social, historical and theoretical context have their own worldview, which is called a paradigm. Within each paradigm, preferred methods can be used to guide the research. A paradigm is like a scaffolding for the questions that we ask and how we answer them (Ryan, 2006). The paradigm of post-positivism is sometimes called an indirect form of positivism (Giacomini, 2010). However, it has a more open view of examining real-world problems. For example, the meaning behind a phenomenon can be highlighted in an attempt to clarify social concerns. Practice and theory can be combined and many different methods can be used to collect and analyse data (Henderson, 2011; Ryan, 2006). This means that the "social" world can be evaluated from both objective and subjective perspectives (Mertens, 2005), which is known as dualism. However, post-positivism is neither objective nor subjective and do not prefer one perspective over the other. Instead, the multiplicity and complexity of humanity are underlined (Ryan, 2006). Ontology is the study of being, which refers to our beliefs pertaining to reality, our existence and the nature of value. It ranges from realism to idealism (Birks, 2014; Giacomini, 2010). Idealism implies that reality exists independently of the subject (Howell, 2012) and qualitative researchers try to understand these concepts. Epistemology attempts to explain possible ways of understanding the reality of how we get to know about phenomena (Birks, 2014; Giacomini, 2010). Post-positivism suggests that social science is often socially constructed, which suggests that such knowledge cannot be neutral. Thus, it cannot be separated from an ontology or personal experiences. Therefore, it is important to reflect on the researchers' epistemology and what it brings to the research. Researchers within the post-positivism paradigm conduct research and learn among other people instead of learning independently (Ryan, 2006). Thus, truth can be understood as a reflection of reality or something that provides an understanding of reality (Howell, 2012). As expressed by Birks (2014), "…many things are believed to be true or false, but it becomes knowledge when we believe it is true." Research conducted within the paradigm of post-positivism does not come up with a single truth. However, conclusions are drawn, which highlights the complexity of the experiences. Theories are often seen as results within the post-positivistic paradigm. Notably, they usually have a "situation-producing approach" (e.g., interventions to manage health threats). Therefore, research within the nursing field often falls under the paradigm of post-positivism (Weaver & Olson, 2006). This methodology refers to a broader research strategy and can include different methods that support the research question (Howell, 2012). There are mainly two methodologies within the paradigm of post-positivism: qualitative description (QD) and critical realism. The main difference between these methodologies is the interpretation of reality. Since this thesis partly aimed to describe the contrasts between men's, their partners' and health care professionals' experiences of screening-detected AAAs, this study falls under the QD methodology.

3.3 Qualitative description

In QD, reality is viewed from two levels: the *empirica*l and the *actual.* The empirical level refers to what we can see and observe in the surrounding context or something that we can discuss among one another. The actual relates to something that occurs regardless of our perceptions or knowledge about it. According to Sandelowski (2000), QD attempts to explain and describe the "facts" of a phenomenon or experience. However, the "facts" must be in a specific context to have meaning. Descriptions of the "facts" depend on the participants' perceptions, feelings, understanding and sensitivity, while all descriptions include an interpretation of them.

According to Stake (2010), "qualitative case study (QCS) is not a methodological choice but a choice of what is to be studied" (p. 435). However, other researchers have suggested that QCSs are "paradigmatic bridges" that can fit into different paradigms (Carolan et al., 2016). Therefore, QCS can be relevant regardless of paradigm. In this thesis, QCS was viewed as a method.

3.4 Qualitative case study

The purpose of conducting a QCS is to develop a deeper understanding of a phenomenon in a "real-life context" (Crowe et al., 2011). It can either test a theory (Anderson, 1983; Pinfield, 1986), develop a theory (Eisenhardt & Graebner, 2007) or render a description (Gustafsson, 2017). The QCS method is popular for health and social science (Baskarada, 2014; Carolan et al., 2016). Moreover, it is an appropriate method to use when answering "how or why" questions, or when the boundaries are unclear between the case and the context but the context is of importance (Baxter & Jack, 2008; Yin, 2018). Notably, there are many different definitions of what a case study is. For example, a case can refer to a process, event, situation, phenomenon, person or organisation, among others (Baxter & Jack, 2008; Crowe et al., 2011). The definition used in the present thesis is based on the definition of Miles and Huberman (1994): “a phenomenon of some sort occurring in a bounded context”. In the present thesis, the case was “*The perspectives of screening-detected AAA*”. Each case has one inside and one outside boundary with specific components. A case also needs to be bounded and suggestions of boundaries can include time and activity, time and place, or the context (Baxter & Jack, 2008; Miles & Huberman, 1994; Stake, 2005; Yin, 2018). The context in which a phenomenon occurs must be described in a QCS. In this study, the context was the *“screening context”*.

There are different types of QCS and Yin (2016) and Stake (2013) used different terms to describe them. Yin (2018) defined them as explanatory, exploratory or descriptive, while Stake (2005) defined them as intrinsic, instrumental or collective. Furthermore, a QCS can be a single case study or a multiple case study with or without embedded sub-units. The sub-units are situated within the cases. The data can be analysed separately within each sub-unit and across them, which was done in this study. Since the phenomenon in this study shares the same context (Baxter & Jack, 2008), it will be illustrated as a single case study with three embedded sub-units. The three embedded sub-units consist of *men having a screening-detected AAA*, *partners living with a man that has a screening-detecting AAA* and *health care professionals working with AAA screening*. The exploration in the sub-units facilitates a detail level of inquiry into the phenomenon.

3.4.1 Setting and context

The components outside the case can be defined by the context in which the phenomenon takes place. The context can refer to a historical, social, or cultural context or specific time or place (Stake, 2005). However, the context around the case must be set and described so the process of research can be understood and followed (Crowe et al., 2011). Each case study has its own context (Stake, 2013) and the context for this study was included *the AAA screening.* Notably, AAA screening is part of the health care system in Sweden.

The QCS was conducted in Sweden, a Scandinavian country in northern Europe. Sweden is a parliamentary democracy. The population was estimated at 10.3 million people in 2019 and the main language is Swedish. Stockholm is the capital and largest city, followed by Gothenburg and Malmö. Malmö is located in the southwest part of Sweden and has 344,166 inhabitants (2019). It is a multicultural city with more than 184 nationalities (SCB, 2019).

Health care in Sweden

Sweden has three independent governing levels: government, county and municipality. The county level is the main provider of health care services. Notably, Sweden is divided into 20 counties. The health care system in Sweden is a socially responsible system that aims to ensure the health of all citizens. The service is based on three principles: 1) *the principle of human dignity*, which means that all humans have an equal right to dignity and the same rights to health care, regardless of social status; 2) *the principle of need and solidarity*, which refers to those with the greatest need having priority in the health care system; 3) *the principle of cost-effectiveness*, which means that there should be a reasonable relationship between the cost and effects regarding improved health and QOL. While most health care in Sweden is tax-funded, there are charges (maximum of 1200 Swedish krona (SEK)/year (1060 Hong Kong dollars (HKD)) when patients require specialist care. The maximum charge per visit is 400 SEK (350 HKD) and all operations are free of charge (Swedish Institute, 2017).

The AAA screening context

Abdominal aortic screening in Sweden has been introduced nationwide and started in Malmö in September 2010. Since then, 28062 men have been invited, 19037 have been screened and 311 aneurysms have been detected. Out of the 311 aneurysms, 24 had a diameter of ≥ 55 mm and underwent an elective operation (Malmö AAA Screening Database, 2017). All men from the southwest part of Skåne receive an invitation for a screening examination of their aorta when they turn 65 years old. The invitation is written in Swedish with an internet link provided for information in other languages. Men who do not attend the first screening appointment are reinvited once. The invited men have the opportunity to change the time of the screening appointment. The fee for the examination is 120 SEK (102 HKD). The U/S examination is carried out by a biomedical scientist or by registered vascular nurses (RNs). These nurses have completed a special training course in U/S techniques. The screening team also consists of medical physicians. The average examination length is 10 minutes. The RNs meet the men in the waiting room and follow them to the examination room. The men then remove the clothes from their upper body and lie down on a pallet. The RNs then place a U/S probe onto the abdominal area and quickly receive the U/S examination results. The definition of an AAA is a diameter of ≥ 30 mm using the leading-edge to leading-edge technique, which measures the distance between the anterior outer wall and the posterior inner wall of the aorta (Singh et al., 1998). The examiner then informs patients with a diameter of ≥ 30 mm of their condition during the appointment. Then, 1 to 4 weeks later, they will have an appointment for a consultation with a vascular surgeon or angiologist. For this appointment, patients must pay 300 SEK (260 HKD). All patients with AAAs are given pharmacological secondary prevention with statins, antiplatelet therapy and antihypertension medicine if they have hypertension (Williams et al., 2018). The men diagnosed with an AAA will be followed with regular U/S examinations at a frequency based on the diameter of the aneurysm. Aneurysms with a diameter of 30–34 mm are followed up every 36 month, while those with a 35–39 mm diameter are followed up every 24 month. Diameters of 40–44 mm are followed up annually, while diameters of 45–55 mm are followed up every 6 months or more often. These intervals are based on recommendations from either the medical angiologist or vascular surgeon (local recommendation in Malmö). The cost for each follow-up appointment is 200 SEK (175 HKD).

3.4.2 Sampling

The cases are mostly selected based on their uniqueness according to the phenomenon and defined as follows by Stake (1995): “In case studies, sampling applies to selecting the cases and selecting the data sources that best help to understand the case” (p. 56). Sampling refers to the act, process or technique of selecting a representative part of a population with specific characteristics that answer the study questions (Ravitch, 2016). Miles et al. (2013, p. 35) define this as “taking a smaller chunk of a larger population”. However, different qualitative research techniques can be used, depending on the methodology and aim of the study. A purposeful method is a commonly used method where the researcher selects certain participants in a special context that can provide information-rich data according to the aim of the study (Gentles et al., 2015; Gray et al., 2017; Miles et al., 2013). The study population in this study was men with screening-detected AAA, their partners and health care professionals working with AAA screening.

3.4.2.1 Inclusion criteria

Men: The inclusion criteria were men with screening-detected AAA ≤ 55 mm at the Department of Cardio-Thoracic and Vascular Surgery at Skåne University Hospital between the years 2010 and 2017.

Partners: The inclusion criteria for this group were partners (either married or living together) to men with an AAA ≤ 55 mm that were attending regular follow-ups via the screening programme at the Department of Cardio-Thoracic and Vascular Surgery at Skåne University Hospital between the years 2010 to 2017.

Health care professionals: The inclusion criteria for this group were professionals working in AAA screening in Sweden.

3.4.2.2 Exclusion criteria

Men and partners: The exclusion criteria for men and their partners were individuals with dementia or severe psychiatric disorder diagnosis and individuals unable to speak. Men and their partners were also excluded if the men had undergone surgical treatment of their AAAs.

3.4.3 Participant recruitment

Men

Since the purpose of this study was to describe men's perspectives and experiences of living with a screening-detected AAA, a purposeful sampling method was used. It was desirable to recruit men with maximum variation, which means to include men with different characteristics, which can help to recognise patterns in the analysis. (Miles et al., 2013).

While the required sample size was difficult to estimate, a benchmark using Sandelowski (1995) sample size recommendation for QD studies—i.e., between 15 and 30 interviews before reaching data saturation—was used. Data saturation typically refers to reaching informational redundancy to the point where additional interviews will add little or nothing new to the data. However, data saturation also depends on the quality of interviews and contact with participants (Gentles et al., 2015). Based on previous qualitative studies within the screening context, a response rate of approximately 60% has been observed (Hansson et al., 2012). The PhD candidate achieved consent from the Head of Department (July 2017) to use the local screening database (Filemaker Pro®) to recruit participants for the study. Filemaker Pro® is a database where all the patients with a screening-detected AAA are registered chronologically. This led to heterogeny sampling in regards to the time the men had been under surveillance. A total of 61 patients were randomly and intermittently asked to participate in the present study. Among these, 32 responded positively and expressed their desire to participate. Out of these 32 responses, two patients had already undergone surgical treatment for their aneurysms, while one was excluded because of his psychological condition, one cancelled his interview due to health problems in the family and one never answered the phone call to arrange an interview. Altogether, 27 interviews were conducted. However, one interview was interrupted because the interviewer realised that the man was unaware of his aneurysm and another was excluded due to technical problems. Thus, the analysis was based on 25 interviews. To ensure voluntary participation, initial contact was made via a written mail invitation in Swedish (Appendix 1). The invitations were sent to selected participants along with a prepaid envelope and answer sheet. The participants were asked to express their willingness to participate and send back the answer sheet for further contact from the PhD candidate. The contact information was given to the PhD candidate and two of her supervisors (CK; EC) in case the participants had any questions or required further information. If no confirmation was received after a couple of weeks, the participants were invited a second time with a new letter (Appendix 2). After receiving consent to participate, the PhD candidate contacted the participants to arrange appointments for interviews. During these phone calls, the purpose of the study was explained and clarifications were made if needed. Further verbal and written information was provided about the study to participants and their written consent was obtained (Appendix 3) at the time of the interviews. Before each interview, participants were once again informed that participation was voluntary and that they could withdraw at any time without providing any reason (Figure 4).

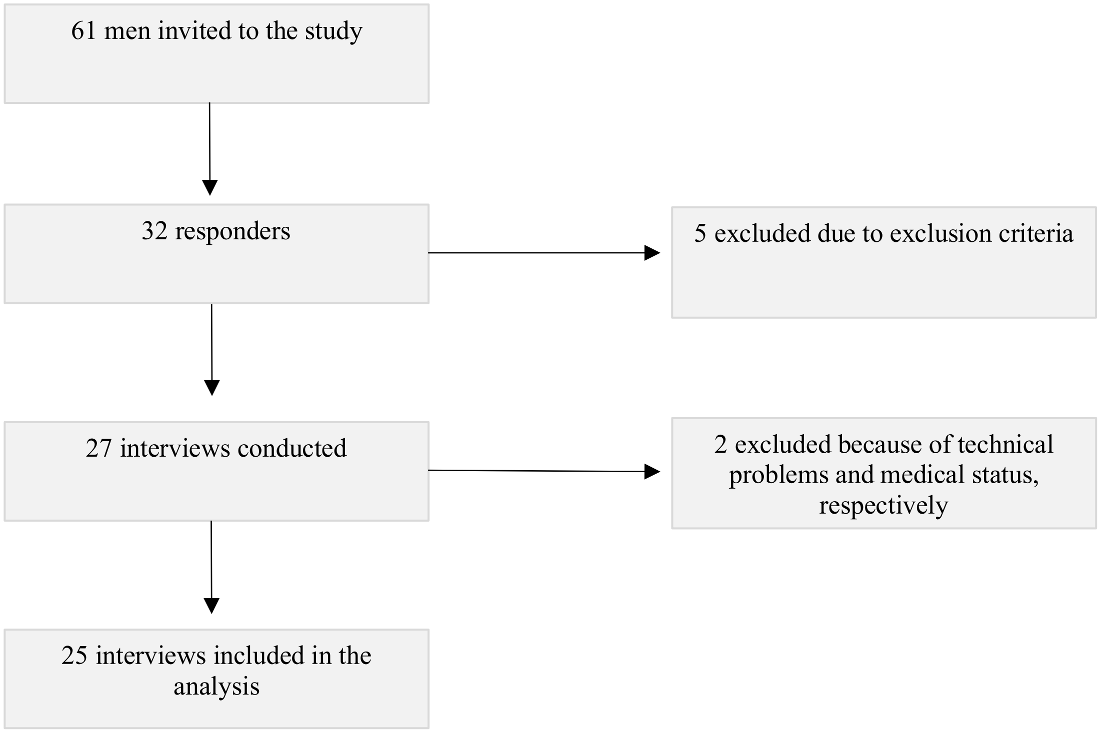

Figure 4 Illustration of the recruitment of men diagnosed with AAAs.

Partners

The recruitment of partners initially involved a convenient sampling method, which was chosen due to its accessibility (Miles et al., 2013). The men with AAAs who participated in the interviews (described in the previous section) were asked for consent to invite their partners for another separate interview. Overall, 14 men were asked for consent to be able to invite their partners. If the men accepted, further contact was made with their partners. An invitation and information sheet, written in Swedish (Appendix 4) outlining the study was sent to the 14 partners with an answer sheet and a prepaid envelope. Contact information for the PhD candidate and two of her supervisors were provided if further clarification was required. Overall, 12 of the 14 partners replied and wanted to participate in the interviews. New invitations (Appendix 5) were sent out to the remaining two partners but no response was received. The PhD candidate contacted the 12 partners and made arrangements for the interviews. The partners chose the time and place for the interviews. Written consent was obtained before the interviews (Appendix 6). After these 12 interviews, data saturation was still not reached and further recruitment was needed. Men with a screening-detected AAA were first randomly identified through the screening database Filemaker Pro® and asked for consent via mail to invite their partners to participate in the current study (Appendix 7). After obtaining consent from the men, the partners were invited via mail. In total, 34 men were asked for consent. Ultimately, sixteen of them consented to inviting their partners. Sixteen partners were invited and 75% responded positively by indicating their desire to participate in the study. However, two of their men had undergone surgery for their aneurysm and were thus excluded. Moreover, one of the partners could not be reached over the phone. In total, 21 interviews were conducted with partners (Figure 5).

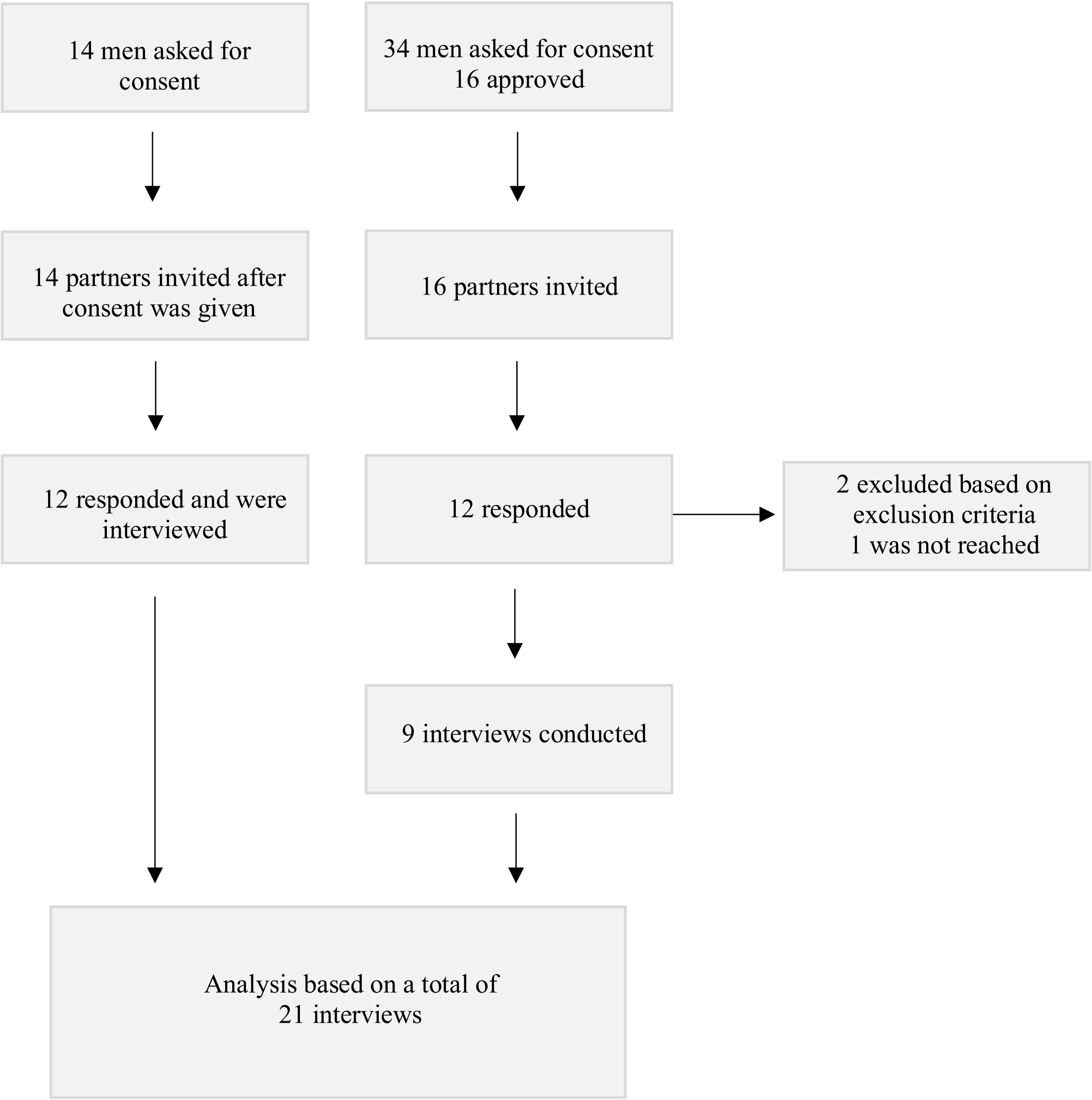

Figure 5 Illustration of the recruitment of partners.

Health care professionals

There is no optimal number of participants for focus groups. Some authors have suggested six to eight participants (Krueger & Casey, 2009), while others have suggested that a smaller amount of participants are easier to handle as a researcher and moderator (McLafferty, 2004). The participants were selected based on their knowledge of or experience with a specific topic (Conn et al., 2001), while study participants were selected based on their knowledge and experience of working with patients who attending screening programmes.

Together with one of her supervisors (CK), the PhD candidate decided which vascular clinics in Sweden to contact. Invitations for interviews along with a brief explanation of the study (Appendix 8) were sent to six contact persons. They were asked to respond either through email or a phone call; otherwise, a reminder email was sent. One clinic responded that they were interested but did not have the time to participate. Another clinic noted that they had a slightly different organisation for the screening of patients and thus did not consider it suitable to be involved in the interviews. Two of the clinics asked to contact other people instead, which was done with a positive outcome. After the contact persons' responses, the PhD candidate contacted them via telephone to arrange the interviews. The interview dates were announced well in advance so that the participants could make scheduling arrangements. Either the contact person at each clinic forwarded the email to their colleagues or the PhD candidate received the email addresses and sent out the emails (Appendix 9). In total, five interviews were conducted at four different centres in Sweden (i.e., Malmö, Gothenburg, Uppsala and Gavle) with a total of 14 health care professionals.

3.4.4 Data collection

Three separate data collections served as fundamental parts in the embedded units of the case: individual interviews with the men, individual interviews with the partners and focus group interviews and one individual interview with the health care professionals.

Collecting qualitative data via interviews is a commonly used technique. An interview can be defined as “social interaction with the interviewer and interviewee sharing and constructing a story and its meaning; both are participants in the meaning making process” (Holstein & Gubrium, 1995, p. 8). The main goal of an interview is to collect “insight into the individuals’ lived experiences, understand how participants make sense of and construct reality in relation to the phenomenon, event, engagement…” (Ravitch, 2016, p. 146). In qualitative research, it is of utmost importance to focus on the participants’ experiences, relate those experiences to other participants in the same context and receive a range of different perspectives and experiences about the specific phenomenon.

Data collection from men

All of the 27 (2 excluded) individual interviews with men who have a screening-detected AAA were conducted in Swedish between July 2017 and December 2017. The interviews were arranged in accordance with the men’s wishes: 12 were conducted in participants’ homes, 12 were conducted in a room at a University, 1 was conducted at a man’s workplace (in a separate room) and one was conducted in an office setting at the clinic. The PhD candidate conducted the interviews, which were digitally recorded after obtaining consent from the patients. Before the interviews started, the men were once again informed about the purpose of the study and told that they could withdraw at any moment without providing a reason. They were also asked to give examples and explain their replies with as much detail as possible and told that the interviewer would attempt to make them give more detailed explanations. Some reminder notes were taken during the interviews, which participants were also informed about.

The interviews followed a semi-structured interview guide, which is provided on the following page (the Swedish version is provided in Appendix 10). The interviews started with the opening question “Can you please tell me what it is like to live with the knowledge of having an AAA?” When conducting semi-structured interviews, the researcher had an instrument as a guide with questions that were provided to everyone; however, specific follow-up questions could also be written down if needed (Ravitch, 2016). In this study, a few examples of follow-up questions were written down as reminders for the PhD candidate. According to Sandelowski (2000), minimally to moderately structured open-ended questions are appropriate in QD. However, the questions in the interview guide mainly focused on the patients’ experiences of living with an AAA. These questions also covered topics about their lifestyle and its effect on the AAA, the information they received from health care workers and their thoughts about support from the health care system regarding their AAA. During the interviews, further probes were identified. One of the goals during the course of the interviews was to encourage participants with follow-up questions in order to prompt further explanations or obtain more detail about the topic being discussed (Bourgeault et al., 2010). The interviews lasted between 15 and 108 minutes, with a mean time of 41 minutes. Notably, two (i.e., one for the man and one for the partner) pilot interviews were also conducted. Following a discussion with the thesis supervisors, data from the pilot interviews were included in the analysis.

Interview guide for men living with a screening-detected AAA

Introduction

- Aim of the study.
- Part of a doctoral thesis.
- The interview will be recorded.
- Participation is voluntary and you have the right to withdraw at any time.

Opening question

- Can you please describe what it is like to live with an abdominal aortic aneurysm?

Interview questions and transition with probes

- When you received the invitation to the screening, what made you decide to attend?
- Can you please tell me more about the day when you received the diagnosis?
- Can you please describe the time from when you got the first invitation up until today?
- Please tell me what you knew about abdominal aortic aneurysm when you received the invitation.
- Can you please tell me what you know about abdominal aortic aneurysms today?
  - ⇒ Regarding the generic part of the diagnosis.
- Please describe the information provided by the health care professionals.
  - ⇒ Did they give you any restrictions? If so, what kind of restrictions were made/given?
- According to the knowledge you have today, do you have any suggestions for health care professionals regarding other kinds of information or support for men like you with an AAA?
- Can you please further describe the information you got in the invitation to the screening?
  - ⇒ Was there anything else that you would have appreciated knowing before you decided to attend the screening examination? If so, can you give some examples?
- Can you describe how thinking about your aneurysm affects you?
  - ⇒ During special situations.
  - ⇒ How do you handle these situations?
  - ⇒ How often do you have these kinds of thoughts?
  - ⇒ With whom do you share your thoughts and concerns?
- Over the years you have been living with the knowledge of your aneurysm, have your thoughts changed? How?
- Please tell me about the support that you got from the health care professionals.
- Can you tell me whether you have made any changes in the way you live?
  - ⇒ Changed your lifestyle, smoking habits, exercise, diet?
  - ⇒ Please tell me what you know about the relationship between smoking and abdominal aortic aneurysms.

    - ⇒ Would you appreciate getting further professional support for changing your lifestyle?

- o What do you appreciate most about the abdominal aortic aneurysm screening programme? And what do you appreciate least?
- o With the knowledge you have today, would you attend screening again?

Further examples of probes that were used to gain a deeper understanding

- o Can you describe/explain…?
- o Can you please clarify…?
- o Can you tell me more about…?

Summary

- o You have told me about…?
- o Your experiences of living with an abdominal aortic aneurysm are…
- o Is there anything you would like to add?

Data collection from partners

The procedure described in the previous section was followed for data collection from the 21 partners. However, the opening question was changed to “Can you please tell what it is like to live with a man that has an AAA?”. The interviews then followed a semi-structured interview guide, which is provided on the following page (the Swedish version is provided in Appendix 11). The individual interviews were conducted between August 2017 and February 2018 in accordance with the partners’ requested interview locations. Fifteen interviews were conducted in the partners’ homes, five were conducted in a private room at a University and one was conducted in a partner’s workplace. The interviews lasted between 12 and 70 minutes (mean time: 32 minutes). Table 5 presents data on the characteristics of the participants who participated in individual interviews.

Interview guide for partners

Introduction

- Aim of the study.
- Part of a doctoral thesis.
- The interview will be recorded.
- Participation is voluntary and you have the right to withdraw at any time.

Opening question

- Can you please tell me what it is like for you to live with a man that has a screening-detected abdominal aortic aneurysm?
    - ⇒ Why do you think it affects you?
    - ⇒ Why do you think it does not affect you?
    - ⇒ What does it mean to you?

Interview questions and transition with probes

- When your partner got the invitation for the screening, what was your reaction?
- Can you tell me what you knew about abdominal aortic aneurysms at the time?
- Please tell me what you know about it today.
    - ⇒ Where did you get this information from?
    - ⇒ Would you like to know more about the diagnosis?
    - ⇒ Why do you not want to know more about the diagnosis?
    - ⇒ Can you please tell me what you know about the generic aspects of the diagnosis?
    - ⇒ Please tell me about the information you have received from the health care professionals at the AAA screening.
- Can you please try to remember what you were thinking the day he attended the first screening examination and got the diagnosis? How did you react?
- Have your thoughts changed over time from the day he got the diagnosis up until today?
    - ⇒ What is the reason for that?
- Is there any special situation when you think more about the abdominal aortic aneurysm?
    - ⇒ How often do you have these kinds of thoughts?
    - ⇒ Can you please try to clarify what kind of thoughts/feelings you have during these special situations?
    - ⇒ How do you handle these kinds of thoughts/feelings?
    - ⇒ Is it something that you discuss together?
- Please tell me about the information you have received regarding lifestyle concerning the abdominal aortic aneurysm.
    - ⇒ Please tell me about your lifestyle.
    - ⇒ Do you smoke/Have you previously smoked?
- Can you please tell me if your life as a couple has changed due to the knowledge of the abdominal aortic aneurysm? How has it changed?
- Has your life changed? How has it changed?
- Please tell me about your greatest challenge in terms of living with an awareness of your partner’s abdominal aortic aneurysm.

- Can you please tell me how you support your partner?
- Do you know anyone else with an abdominal aortic aneurysm? What experiences have you shared?
- With the experience that you have of being a partner to a man that has a screening-detected abdominal aortic aneurysm, is there anything that the health care professionals/providers can do to improve the situation for you or your partner? What kind of support would have been appreciated in your situation?

Further examples of probes that were used to gain a deeper understanding
- Can you describe/explain…?
- Can you please clarify…?
- Can you tell me more about…?

Summary
- You have told me about…
- Your experiences of living with a man that has an abdominal aortic aneurysm are…
- Is there anything you would like to add?

Table 5 Demographic characteristics of the participants.

	Partners **n=21**	**Men** **n=25**
Age mean (range)	67 (57–77)	69 (65–72)
Origin of birth n		
Sweden	20	22
Outside Sweden	1	3
Smoking n		
Current	3	8
Cohabitation n		
Married	20	17
Living together	1	1
Single		7
Education n		
Primary school	2	9
Upper secondary school	13	7
University	6	9
Employment status n		
Working	7	1
Retired	14	24

Data collection from health care professionals

The collection of data from health care professionals was mainly performed through focus group interviews. However, one was performed as an individual interview since this clinic had a slightly different screening organisation. The advantages of focus group interviews are that they can provide the opportunity to gather more data in a shorter amount of time. The participants can also share their ideas and thoughts and it is easier to stimulate ideas when compared to individual interviews (Lederman, 1990). The interviews with professionals from the screening teams followed an interview guide to cover the issues, which is presented on the next page (the Swedish version is provided in Appendix 12). The questions were mainly based on data from the men and their partners for the purpose of gathering practitioners' opinions and perceptions regarding the participants' experiences with the screening and living with a screening-detected AAA, while also highlighting their views on the care provided. Example of questions include "Based on your experience, can you explain the patients' or their partners' requests for support?" or "Based on the interviews with the partners or patients, we found that they might have further requests for information… can you tell us your opinion or your impression about this?". The question guide was designed in advance and followed the elements suggested by Lederman (1990): 1) An introduction, which provided the purpose of the interview. The moderator and assistant were introduced (if any) and the ground rules for the interviews were given (e.g., interviews being confidential and consent forms being signed); 2) The first question was the open question "Based on your perceptions, how do the patients experience the screening and message about their diagnosis?". Lederman (1990) refers to a warm-up or an ice breaker question; 3) This question was followed by several questions that attempted to elicit the experiences of the health care professionals; 4) The interviews ended with a summary.

Three of the interviews were moderated by the PhD candidate and the remaining two were moderated by one of her supervisors (EC) since these groups included former colleagues of the PhD candidate. The role of the moderator was to include and encourage members to express their opinions, ask questions and follow-up questions and try to lead the discussion with minimum interactions. The PhD candidate was an assistant in two of the group interviews. In the third interview, an external assistant helped to record the sequences of the conversation, made minor notes and statements and asked participants to add further questions at the end of the interview, if necessary. The assistant also helped with the audio recording during interviews after obtaining the consent of participants. When conducting focus group interviews, there is a risk that some of the participants may be more dominant compared to the rest of the group. The opposite can also be experienced, with some participants being very silent (Yin, 2016). Notably, the dynamics in a group of colleagues that know each other can lead to participants responding differently compared to how they would in an individual interview. On the contrary, knowing each other can also lead to a more open discussion (Moore et al., 2015). While there was a noticeable imbalance in some of the groups, this was mainly based on participants' years of experience with the screening service. All interviews were conducted in Swedish.

Interview guide: Focus group interview with health care professionals working with AAA screening

Introduction:

- Welcome to a focus group discussion where we will try to shed light on men with screening-diagnosed AAA and their partners' possible need for support and information based on your clinical experience.
- Remember that there are no right or wrong replies to the questions.
- What is mentioned during this discussion remains confidential.
- You are asked to respond to your colleagues' comments, but we try to talk one at a time.
- The interviews are recorded.

Opening Question:

- Based on your experience, how do you perceive men diagnosed with an AAA experience their situation with their relatives?

Supplementary questions (prompts):

- Could you give examples of…?
- What is your opinion? Do their experiences change over time as they go through the screening? If so, how?
- Do you think their experiences change if the AAA grows?

Interview Questions:

- How do you feel patients and their relatives experience the information you provide?

Supplementary questions (prompts):

- Would you be able to give examples of the information you provide?
- How do you follow up on this information?
- Can you tell us about the information you provide about secondary prophylaxis (incl. smoking cessation)? Do you think this is part of the treatment for these patients?
- If you were to change anything about the information you provide, what would it be?
- If the patients have any questions for you, what are they?
- How is the balance between oral and written information?
- What kind of information is given during the screening examination and how does it differ from the medical consultation they have with the medical doctors?

- In addition to the information you give patients and their relatives, tell us what your support for them looks like.

Supplementary questions (prompts):

- Could you tell us more about…?
- Have your views on supporting patients and their relatives changed during the time you have been working in screening?
- What is the most important thing to remember when supporting the men and their partners?

- Do you have any examples of information or support that has meant a lot to patients or their partners?
- Who can the patients or their families contact in between screening examinations if they have further questions?
- What is your opinion on your experiences in caring for the men with AAAs and their partners regarding support…Do you think there is a need for another type of support for these men and their partners? If so, what should it look like?
- What are the men and their partners most worried about?
- What is exceptionally good about the screening programme?

- If you had the opportunity to change something that could improve patients' and their relatives' situations, what would it be?

- What do you think is most challenging for patients living with AAAs and their relatives?

In Summary:

- You have told us/me that you experience the information and support for patients as…
- Your perceptions of patients' situations are…
- If anyone wants to add something, you are welcome to.

3.4.5 Analysis

The analysis of QCS is the part of method description that requires further development and better description (Yin, 2018). Various analysis approaches exist for QCS, such as grounded theory, phenomenology, thematic analysis and narratives (Ayres et al., 2003; Larsson et al., 2019; Saladin et al., 2018) Notably, “general techniques” such as pattern matching, time series analysis, linking data to propositions and cross-case synthesis are suggested by Yin (2018). While Stake (1995) refers to “categorical aggregation and direct interpretation” and “ finding pattern”, the same author also highlights that “each researcher needs, through experience and reflection, to find the forms of analysis that work for him or her” (Stake, 1995, p. 77). The utilised analysis approach depends on the purpose and the type of QCS conducted (Baxter & Jack, 2008). This provides independent researchers with the opportunity to decide on an applicable approach and organise the data in a manner that is in line with the design of the conducted case. However, the general aim of conducting and analysing a QCS is to increase understanding of a phenomenon and be able to explain and describe the uniqueness of the case and its specific context. Notably, two approaches have been highlighted for this purpose: the “case-oriented” and “variable-oriented” approaches (Miles et al., 2013). The case-oriented approach focuses on the whole case and its associations—first within the cases and then later between the cases. The variable-oriented approach is theory or concept driven and focuses mainly on the relationship between the different variables or concepts involved (Ragin, 1987). It is also possible to combine these approaches, which is known as “stacking comparable cases” (Miles et al., 2013). Since the present study was a single case study, the approach of comparing cases was utilised between the embedded units instead, while “within-case” analysis was conducted within each embedded unit (i.e., *"The men", "The partners"* and *"The health care professionals"*). The "within" analysis describes the content and develops a deeper understanding within each of the aforementioned embedded units. Furthermore, it leads towards the whole case and to the "cross-analysis". In the " cross-analysis" comparisons and associations can further enrich the understanding of the case (Miles et al., 2013). Notably, the case analysis should be treated as one "unit of analysis" (Baxter & Jack, 2008; Miles et al., 2013; Saladin et al., 2018).

Initially the data analysis process for this study was first comprehensively conducted within each of the embedded units. This was followed by a cross analysis between the embedded units focusing on the differences in their experiences (Figure 6).

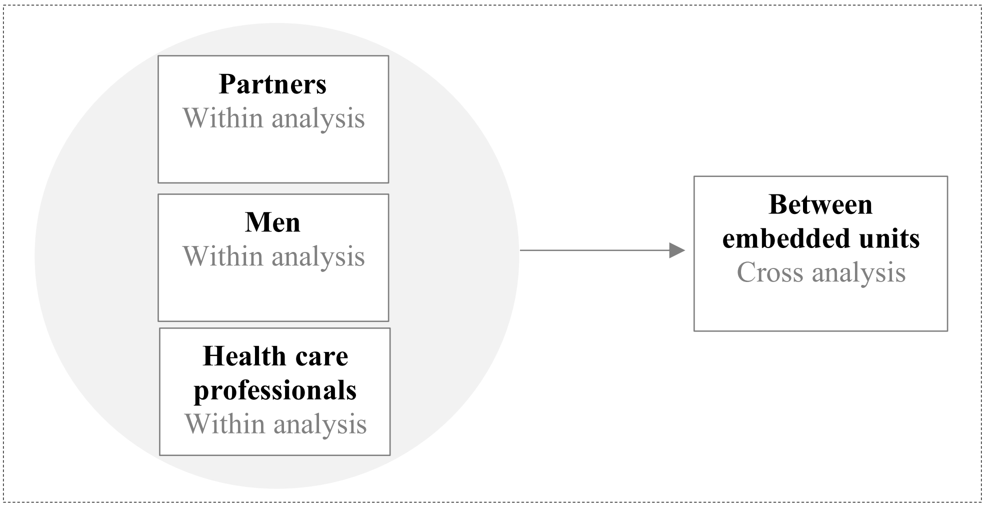

Figure 6 The analytical procedure: Within analysis of the embedded units followed by a cross analysis between the embedded units.

The goal of analysing qualitative data is to interpret data and go beyond the descriptions from interviews. This was defined by Bernard et al. (2016) as "the search for patterns in data and for ideas that help explain why these patterns are there in the first place" (p. 109). Qualitative content analysis (QCA), is a commonly used method for analysing data in health care research and is also recommended for use with data in QD (Sandelowski, 2000). While the foundation of QCA stems from the journalistic field (Leung & Chung, 2017), its goal is "to provide knowledge and understanding of the phenomenon under study" (Downe-Wamboldt, 1992, p. 314). It is a process used by researchers to interpret the meaning or usage of written or visual data. In QCA, the data are converted from codes into categories. The technique used for organising the data can involve asking questions such as "What is it?" to gain a further deeper understanding of the meaning behind phenomenon questions such as "What is it about?", "How is it happening?", "Where is it happening?" and "What are the consequences?", which can be asked during the analysis. Asking questions about meanings provides a deeper understanding and richer view of the phenomenon under investigation (Sandelowski, 2000). There are three different approaches for QCA: 1) Conventional content analysis, 2) Direct content analysis 3) Summative content analysis (Hsieh & Shannon, 2005). The research questions guide the decision on which approaches should be used (Leung & Chung, 2017). The summative approach often stems from quantitative data to explore the contextual use of specific words, while the analysis can often remain in the manifest phase. The direct approach is used to add creditability to a theory where codes and categories originate from the literature and data are often analysed deductively. Since this is a reasoning approach that can lead to new possibilities and probabilities, the conventional QCA approach is often used when there is limited previous knowledge about a phenomenon or when there is no existing theory (Elo & Kyngäs, 2008). This is also known as the inductive reasoning approach. The word inductive comes from the Latin word *inducere*, which means "to lead to or bring out". Through the inductive reasoning approach a narrow concept or phenomenon can serve as a starting point that can grow and develop new facts or theories. The data commonly originates from semi-structured interviews where open-ended probes such as “Can you tell me more about…?” are used (Hsieh & Shannon, 2005). When analysing manifest data, researchers stay close to the text and describe what the participants say. In latent analysis, researchers attempt to interpret the meaning of the data. To create categories, manifest analysis is recommended in QD (Sandelowski, 2000). However, there might be a benefit to constructing a latent analysis to further identify and attribute the data to a theory.

According to the research aim of exploring and describing the experiences of partners living with men who have a screening-detected AAA as well as the men’s own experiences, a modified conventional content analysis with an inductive approach was appropriate for analysing both the manifest and latent data. Therefore, the analysis process described by Miles and Huberman (1994) and Miles et al. (2013) was followed to analyse the data from individual interviews with partners and men.

Partners and men

Transcribing verbal data into written data is a routine used in qualitative research that is used to obtain data visualisation for analysis (Gray et al., 2017). All individual interviews with the partners and the men were transcribed verbatim soon after they were conducted. This was done by the PhD candidate in Swedish to maintain all of the slang and other idioms. Notably, there are various ways to analyse qualitative data. In QCS, coding is an initial step in the textual analysis process. A code most often refers to a word or a phrase. “In qualitative data analysis, a code is a researcher-generated construction that symbolises or translates data” (Vogt et al., 2014, p. 13). Depending on the target approach, different code variants can be used (e.g., NVivo coding, descriptive coding, process coding and emotional coding, among others). Data interpretation occurs during coding and when summarising and condensing the data. Furthermore, coding adds value to the research data. To keep records and definitions of the codes used in studies, codebooks are recommended. Alternatively, codes can simply be defined in the software used for analysis (Saldaña, 2013). After researchers become familiar with the material, the analysis process often follows a systematic approach of applying and reapplying codes to the data. The data are then divided, grouped and linked together to give meaning to and develop an explanation of the phenomenon (Miles et al., 2013). The PhD candidate selected chunks from the transcribed data after reading the text line by line. The chunks included a couple of words, statements, sentences or a paragraph. These chunks were then labelled with codes that reflected their meaning. Codes that are labelled chunks are described by Miles et al. (2013) as “first cycle codes”. In the present study, examples of codes for the partners include “worries”, “good to know about the AAA” and “lack of information”, among others. Examples of codes for the men include “surprised”, “expect more information to come”, “reminded of the AAA inside their bodies at follow-up”, among others. The code descriptions were created in NVivo12® for Mac. While the chunks remained in Swedish, the coding process was conducted in English. The labelled chunks were then compared with each other and chunks with similar meaning were grouped to form subcategories and categories. The labelling of these subcategories and categories sharing commonalities and higher order headings is known as “second cycle coding” (Miles et al., 2013). Notably, the categories must reflect different meanings and aspects of the phenomenon under study (Hsieh & Shannon, 2005). The organisation and creation of subcategories were conducted through discussions with supervisors. An outline of the analysis process is presented in Table 6. This process resulted in three categories with eight subcategories. As shown in the literature review chapter (chapter two) of this thesis previous studies emphasising men's experiences of AAA screening in the Swedish context have been conducted. However, studies focusing on the experiences of those living with someone that has a screening-detected AAA have not been found. Therefore, the analysis of interviews with the partners' was conducted before analysing the data from the interviews with the men. As proposed by Yin (2018), while theoretical propositions should lead the analysis, a framework or table of contents can be used in absence of propositions as an alternative model for organising and writing the data (Baskarada, 2014; Yin, 2018). The PhD candidate and her supervisors discussed and made careful considerations before deeming that the content from the inductively labelled chunks from the data on men was reflected, covered and in line with the three labelled categories for the embedded unit of the partners (Table 7). Therefore, the categories from the partners' data were used as a frame to organise the men's first-cycle codes. The analysis process for the data on the men is presented in Table 8. This analysis approach further enabled a cross-analysis (described later) between the embedded units. To ensure that no essential content and elements, related to the aim of the study were excluded from the data on the men when using this approach, the PhD candidate together with her supervisors continuously went back and forth between the transcribed data and labelled chunks during the course of analysis.

Table 6 Analysis process for partner data, including chunks, codes, subcategories and categories.

Chunk	Code	Subcategory	Category
When he got the diagnosis, then I thought "oh no" because I was sitting outside waiting for him. And I was thinking that they went in and came out but he did not come, and I was thinking (sighs) "Oh, is it something?" So, it became a shock even though I had tried to mentally prepare myself for the potential risk because I have customers that have told me about the disease. But suddenly, he got it. Anyway, it was a surprise.	Shock Surprised	Shock and emotional reaction	Experiencing the unexpected
I would like to know the reason for not letting him have surgery. That I would like to know. Why don't they do it now? I then wonder—if it happens (bursts)—shall we drive ourselves to the emergency department or shall we call 112? What shall we do?	Unclear about not having surgery Questions	Peripheral to first-hand information	Experiencing the unexpected
But if he got abdominal pain, I started to feel anxiety and wonder, "Can it be that (AAA) gives him pain?" because, I mean, there are many reasons for abdominal pain. But for sure it is that (AAA) I start to think about.	Abdominal pain Anxiety	Reminder in daily activities	Being constantly reminded of fragility
*I: When they tell you that it has increased greatly and quite rapidly and that it is coming closer to surgery, what do you think about that? *P: That is so good if they (health care) would like to operate on him. Then we don't need to be worried anymore. That is how I think. I: mm P: If he goes through an operation, he will become a new person again. So, I am looking forward to that. I: So, you are looking forward to an operation? P: Yes, because then the worry that something can happen will disappear.	Positive attitude towards surgery Worries can disappear	Ambivalent feelings about surgical treatment	Being constantly reminded of fragility
I am just thinking that it will happen (rupture). What can I do then? And how can I get help fast enough? Those kinds of thoughts. And what can I do so he does not die before reaching the hospital? And what kind of help can I give? But otherwise, I do not think about it that much because you cannot see it.	Preparing for the rupture Questions	Preparing for the worst	Balancing a changing relationship
I: How is your worry expressed? P: (sigh) Thus, I do not tell him about it. I: No. P: I keep it here [pointing at her stomach]. I: mm P: But I do not say anything to C [husband]. Because I think he does not know what it is all about. Or he knows but does not know how fast it can go. I: No. P: I don't know, but I do not tell him about it.	She does not tell him about her worries Protecting him	Protecting role	Balancing a changing relationship

*I=Interviewer; P= Partner
AAA= Abdominal Aortic Aneurysm

Table 7 Descriptions of the content organised under the developed categories for data on the partners and men, respectively.

Category	Content from the data
Experiencing the unexpected	○ **Partners:** Descriptions of their emotions, reactions and thoughts during the entire screening process. This also covered the information/lack of information that reached the partners and how their questions about the AAA affected their lives. *Examples:* Emotions such as sadness, shock, surprise, being pleased to know/be under surveillance, ambivalent feelings, disbelief. ○ **Men**: Descriptions and reasons for the men's emotions, reactions and thoughts during entire the screening process. Furthermore, it also covers content related to the information that the men received, how they understood it, if anything was missing and their general impressions of the information available from the invitation to the screening process. *Examples:* Surprised, baffled, unhappy but still OK, thankful and pleased to be under control, accepting of their fate, wanting more personalised information, pleased with the information provided.
Being reminded of fragility	○ **Partners:** The AAA diagnosis made them aware of their partners' fragility in life during certain situations in their daily lives and also when the AAA expanded and came closer to surgical treatment. While surgical treatment is the only solution that would result in continuing with normal life again, it is also threatening. Furthermore, explanations of their reactions are described. ○ **Men**: Data related to how/when/why AAA diagnosis impacts the men's daily lives. It also covers their reactions and thoughts about surgical treatment and waiting for it whilst being under screening surveillance.
Balancing a changing relationship	○ **Partners:** The partners became emotionally involved in AAA progression and wanted their partner to survive. Therefore, it was important for them to support, protect and do what they could (e.g., live a healthy life) to minimise the risk of expansion and bursts. Furthermore, it describes emotions and thoughts related to their common lifestyles as well as those of their male partner. Additionally, it covers how they protect the men by avoiding conversations about their concerns and worries. It also covers data related to how they prepared for a rupture. ○ **Men:** Data related to their lifestyles/lifestyle changes as well as emotions and thoughts related to the lifestyle impact of AAA diagnosis. It also covers data related to how their lifestyle affects their partner. Furthermore, it covers how they handle emotions and think about the AAA as a couple as well as how the men would avoid talking about the AAA because they did not like to discuss negative things in life to protect their partners.

AAA=Abdominal Aortic Aneurysm

Table 8 Analysis process for data on men, including chunks, codes and categories.

Chunks	**Codes**	**Categories**
I do not have any physical problems due to the AAA—not at all, so I do not think about it. It is not like when you have a toothache or something else—then you feel it all the time.	No physical impacts/comparing it with other diseases Reasons for not thinking about it	Experiencing the unexpected
I only got the information that I should not worry because it (AAA) was not that big. So, it was nothing dangerous. It needed to become closer to 50 mm or something before they would control it more often or do surgery.	Informed that he should not worry, nothing dangerous	Experiencing the unexpected
I think you need more information, written information that you can bring back home, but that is more general information. But I do also want more personalised information, like 'how it is for me'. I mean, this is a dangerous disease.	Wants more information Asks for more personalised information	Experiencing the unexpected
It is not fun to hear that one should not worry all the time. I do know what happens if there is a hole (in the aorta) in 7 to 8 minutes if it is fully open. If you are lucky, you have some fat around your belly that can hold the hole for a short while. But during the last 1.5 years, it (AAA) has not increased. It is 53 mm.	Should not worry Wants to go through an operation, but waiting until it reaches 55 mm.	Being reminded of fragility
I am not the type of person that worries. If it bursts, it bursts. If I am happy, I will survive. For me, knowledge of the AAA has only been an advantage because I do not need to carry things or do other heavy physical duties anymore.	Does not worry, relates it to the person Positive changes (does not lift heavy items anymore)	Being reminded of fragility
What if he (the doctor) tells me that it (AAA) does not look good anymore and to 'quit smoking' at least? Then maybe I should have done it (quit), but my wife's nagging has the opposite effect on me.	Trying to find the motivation to quit smoking His wife's nagging has a negative effect on his smoking cessation	Balancing a changing relationship
I do not like to talk about negative things such as death or disease. Therefore, I avoid talking about it back home.	Avoids talking about the AAA	Balancing a changing relationship

AAA=Abdominal Aortic Aneurysm

Health care professionals

Data from the interviews with the health care professionals working with AAA screening, were collected based on the analysis of the partners' and men's experiences. Therefore, the data were deductively and manifest analysed (Miles et al., 2013). The descriptions, and viewpoints of the health care professionals provided a third perspective for this case study. After transcribing the interviews in Swedish, chunks were coded with "first cycle codes" (e.g., important to balance the information", the men were not prepared for the diagnosis", "stressful", support and meet the men's concerns) from the data, which were related to experiences highlighted by the partners and the men under the categories "Experiencing the unexpected", "Being reminded of fragility" and "Balancing a changing relationship". The analysis process for the health care professionals' is presented in Table 9.

Table 9 Analysis process from data on the health care professionals, including categories, chunks and codes.

Categories	Chunks	Codes
Experiencing the unexpected	All of the men reacted so differently to the diagnosis; therefore, it is a challenge. "I often find the men to be unprepared and they become stressed during the examination. They are not prepared, which might be caused by too much information in the invitation.	It is a challenge because all the men react differently. The men were unprepared for the AAA. Stress during the examination. Too much information in the invitation.
Experiencing the unexpected	It is very difficult with the partners. They seldom join to the screening. But if they do, they are more than welcome. However, they wait outside most of the time. Or when we see family member at the screening, it is when the men have problems understanding the language. But it might also be that they are working, which makes it difficult. But it is up to the couple to decide.	Difficult to involve the partners in the care of the men. Partners are more than welcome to accompany. Couples' decision to decide if the partner should join .
Being reminded of fragility	The most asked question is "Why do the men have to wait for AAA surgery?" Then you need to explain that the risks of going through surgery are more dangerous than the risks of rupture. Even though many understand these arguments, they still find it hard to wait.	The most frequently asked question is about surgical treatment. They (the men) understand the arguments but still find it difficult to wait.
Being reminded of fragility	I do think the men can feel that we are experienced within the vascular care, which makes them calm.	The HCP working experience is positive for the men.
Balancing a changing relationship	At the "follow-ups" (screening examinations), I always try to ask them and follow up on the information about smoking.	Follow up the information about smoking cessation. Both if they have changed habits and if they understood the information.
Balancing a changing relationship	It is our responsibility to support these men and meet their concerns. Many have questions regarding travelling, and I use to say that they can continue to live as they did before they knew about the AAA. But we have also discussed this a lot in the screening group-about restrictions in their daily lives.	Providing support is the HCP's responsibility. Impact on daily life. Discussions within the screening team if concerns exist regarding the responses to the men.

AAA= Abdominal Aortic Aneurysm
HCP= Health Care Professionals

Cross-embedded unit analysis

Since the purpose of this thesis was partly to describe differences in experiences and perceptions, it was necessary to analyse the embedded units', for the men, their partners and health care professionals and to contrast them.

The analysed portions from the three embedded units were compared. Chunks, codes, categories and parts of the analysed text (related to each category) were put in matrices to illustrate their contrasts (Miles et al., 2013; Stake, 2005), which are as presented in Table 10. Similarities and differences in experiences were highlighted and marked with colours. Summaries of these similarities and differences were noted along with corresponding examples as a means to illustrate contrasts. The experience of the men and their partners were used to identify the health care professionals' perspectives, opinions and descriptions of these experiences and differences.

Notably, there are various reporting methods for a QCS. Some approaches involve delivering a chronological report, telling the readers a story or attending to each intention (Baxter & Jack, 2008; Gustafsson, 2017). The analysis of the cross-embedded units for this thesis, was presented as an interpreted text, a short moderated narrative story illustrating the differences between the units and an illustration from the health care professionals' perspectives.

Narratives are commonly used method in social science and have also become popular in health care research. Although narratives have been difficult to define, they can relate to a phenomenon and its process or only the phenomenon itself (Clandinin & Connelly, 2000). This provides an opportunity to capture patients' perspectives on their experiences, which can serve as a window into their world and reflections. This can provide valuable further insights into health care providers meeting the demands of personalised service, support and care (Joyce, 2015; Overcash, 2004).

In the present study, the participants' stories and experiences of living with the awareness of having an AAA/living with someone that has an AAA were the fundamental parts of the modified narratives. Based on the interviews, their stories constructed their realities and served as the basis for shaping the narratives.

Table 10 Examples from the matrices of each category to enable comparisons and contrasts for the cross analysis between embedded units.

<table>
<tr><th colspan="4">Experiencing the unexpected</th></tr>
<tr><th>Codes/chunks (men)</th><th>Codes/chunks (partners)</th><th>Codes/chunks (HCPs)</th><th>Contrasts/HCP perceptions</th></tr>
<tr>
<td>Thankful for the invitation.
Many were surprised about the detected AAA and became shaky. They could not really understand it.
Never heard about AAA until they received the diagnosis themselves.
The reason for developing an AAA was unclear.
Know that AAAs are in a vessel, but not exactly certain where it is located.
Received information about it not being dangerous, while others know it might be dangerous.
They have different needs regarding the type and timing of provided information, but most are satisfied.
Think they will receive more information when the AAA becomes larger or more serious, while others are lacking information.
Trusted the nurses, which made them calm.
If some men did not understand the information, they looked for it on the internet. But this information was also noted as being confusing.
Remembered the size of the AAA and that they will be under surveillance.</td>
<td>Pleased that their men received the invitation to the screening and tried to prepare themselves before the examination.
They were shocked and sad, thought it was unfair.
Wanted to know why the men suffered from an AAA. Lacked both general and detailed information.
The only information they received was about the size of the AAA and that the men would be under surveillance.
Were worried when their men started to look up information about the AAA on the internet. Afraid that such information would further confuse their men.
Seldom joined the screening examination and thus did not meet the health care professionals.</td>
<td>Thought that the men were unprepared for the diagnosis.
Found it difficult to balance the information. They wanted them to understand the seriousness of the AAA and trust the screening surveillance to ensure control.
Found it stressful during the first screening examination.
Too much information to provide in a short time.
Seldom met the partners but noted that they were always welcome to join (up to the couple to decide).</td>
<td>Similarities: Pleased about the invitation to the screening. Pleased to be under control.
Many partners were unclear about what an AAA is and why they develop one.
Differences: The way they expressed their emotions and reactions about screening-detected AAA.
The men were often pleased with the information they received. However, some men expressed that they wanted more detailed information since they were unclear about what an AAA is and where it is located.
The partners expressed that they were lacking information and thought that their men did not know more themselves. This implies that their knowledge was superficial.
The partners did not have any contact with the health care professionals.
HCP perceptions:
The first screening examination was often stressful. There is a lot of information to provide, which the HCPs perceived as difficult to provide since they have to balance the information with the men’s reactions. The HCP suggested that the men were often unprepared for the diagnosis even if they thought the men took the diagnosis with ease.</td>
</tr>
<tr><th colspan="4">Being reminded of fragility</th></tr>
<tr><th>Codes/chunks (men)</th><th>Codes/chunks (partners)</th><th>Codes/chunks (HCPs)</th><th>Contrasts/HCP perceptions</th></tr>
<tr>
<td>Seldom think of an operation.
Take it as it comes.
Compare it to other operations and suggest that it should not be a problem for them to survive an AAA operation.</td>
<td>When the AAA came closer to 55 mm, they thought of an operation more often.
Looking forward to an operation (i.e., the only solution to get rid of the AAA) whilst simultaneously worried about an operation.</td>
<td>The most commonly asked question is why they need to wait for surgery, which can be difficult to explain.
Fully aware that AAAs affect the men. Try to explain and address their worries and concerns.
Try to clarify and inform the men.</td>
<td>Similarities: The reasons for waiting on surgical treatment seem unclear for both the men and their partners.
Trust in the surgeons.
Reminded of the AAA during physical activities, abdominal pain and when it was time for follow-ups.</td>
</tr>
</table>

Looking forward to an operation. Trust in the surgeons. Do not understand why they need to wait for surgery. Wait for operation might be due to economic factors. Leave the control to others. Seldom thought of the AAA. Only thought about it during physical activities, when experiencing abdominal pain and when it was time for follow-ups.	Looking forward to a normal life again. Wondered why they wait for surgery. Some thought they were waiting for a rupture. Trust in the surgeons. Took over heavy physical work from their partner.	Update them during the course of surveillance. Feel comfortable caring for men with AAA. According to the HCP, the main concern was about a rupture of the AAA—tried to explain that they should not worry about that.	**Differences:** Partners expressed a deep desire for their men to undergo an operation so that they can return to a normal life again. However, they also noted that they need to mentally prepare for a negative outcome—especially those with comorbidities or previous negative experiences with operations. Men suggested that they were thinking about the operation on and off, but did not clearly express the emotional effects of this. **HCP perceptions:** HCPs attempted to address the participants' concerns, uncertainties and reactions with both updated information and relevant support, if time and recourses allowed.
Balancing a changing relationship			
Codes/chunks (men)	**Codes/chunks (partners)**	**Codes/chunks (HCPs)**	**Contrasts/HCP perceptions**
Try to protect their partners and other family members by avoiding discussions about the AAA diagnosis. Do not want to bother them or dislike talking about negative things in life, such as diseases and death. Important to spend time together. Knew that they could contact the AAA screening clinic if experiencing abdominal pain. Knew they had the responsibility for their lifestyle and health. They also knew that their lifestyles had emotional impacts on their partners.	Do not talk about their own worries or thoughts that they have about the AAA. Ask how their men felt but did not ask specifically about the AAA since they did not want to remind them about it. Wanted to be prepared and know exactly whom they should call in case of a rupture, what they could do while waiting for an ambulance, and vital signs at an early stage of a rupture. Important to do what they could to prevent the AAA from expanding and live a healthy life. Tried to support the men, which often caused much frustration. They also became upset since the men did not care about their common future together.	Tried to support and provide information, especially regarding lifestyle and other concerns that they knew had impacts on the participants' daily life (such as physical activities). They attempted to explain that they could continue to live as 'normal' (i.e., as they did before the diagnosis of screening-detected AAA). Seldom gave restrictions. This meant that it was a challenge to motivate men to quit smoking. HCPs had limited resources to further support and help.	**Similarities:** Try to protect each other by avoiding asking about the AAA or talking about it in general. Both the men and the partners found it important to spend time together. The way they handle their lifestyles was related to emotions, such as frustration, anger, irritation. **Differences:** The AAA was a reminder of how important it was for partners to spend time together. The partners wanted to be prepared in case of rupture, while the men just knew that they could contact the AAA screening clinic. The partners found it of importance that they had a healthy lifestyle. **HCP perceptions:** Tried to minimise the impacts of the AAA on the participants' lives, support a healthy lifestyle and asked the men to quit smoking. However, they found it difficult to motivate them, since limited recourse was available.

AAA= Abdominal Aortic Aneurysm
HCP= Health Care Professionals

3.5 Computer-assisted qualitative data analysis software

Many different computer-assisted qualitative data analysis software (CAQDAS) are available to store, organise and visualise collected data. Both advantages and disadvantages of using CAQDAS have previously been highlighted. Major disadvantages include their potential to hinder the creativity of the analysis process due to technical functions and that it takes time to learn the functions of a new program. However, some of the advantages of CAQDAS include their ability to store and organise data, manage different data types, display data in matrices and maps, link memos to the text, generate and organise a list of codes and make the research process transparent for researchers and readers (Gray et al., 2017; Miles et al., 2013). These functions were useful in the present study, which used the CAQDAS NVivo12® for Mac. This program was mainly used to store and organise the transcripts, memos and audit trails. Chunks were highlighted and coded in the program and organised in hierarchical order. During the analysis process, mind maps were used to visualise the data under different categories.

3.6 Rigour

The concept of rigour is sometimes interchangeable with validity, quality or trustworthiness. Notably, there are ongoing debates within qualitative research regarding these interchangeable concepts. However, ensuring rigour involves the researcher using strategies to ensure that findings are faithful and in line with the participants' experiences. Various models can be used to assess rigour in qualitative research, such as the models of Kirk & Miller (1986) and Leininger (1985). However, a commonly used model for demonstrating rigour in nursing research was based on the work of Lincoln and Guba (1985) and is also used in QCS (Houghton et al., 2013). Their central terms *Credibility, Transferability, Dependability* and *Confirmability* were thus used to demonstrate and ensure trustworthiness in this study. A summary of the terms and strategies used in this study is presented in Table 10, while further clarification of these strategies will be provided in the following sections (3.6.1, 3.6.2, 3.6.3, 3.6.4).

Table 11 Strategies to establish rigour (Lincoln & Guba, 1985; Shenton, 2004).

Central terms	**Strategies**
Credibility	Interview guide Probes Interview technique Reflexivity of the researcher Purposive sampling with maximum variation Appropriate sample size
Transferability	Clear description of the data collection process Clear description of the data analysis process Clear description of the context and results
Dependability	Independent coding Comparing the codes Clarifying the relationship between the data and the results Triangulation Demographic information about the participants Data saturation Audit trail
Confirmability	Reflexivity Independent coding procedure Audit trail

3.6.1 Credibility

Credibility is concerned with how congruent findings are with reality (Shenton, 2004). Notably, credibility is based on the assumption that there is a single reality and determining whether the assumption is replaced by multiple realities. Multiple realities revealed during interviews must be represented and presented in the study (Krefting, 1991). Credibility can be compared to internal validity in quantitative research (Ravitch, 2016). According to Guba (1981), credibility refers to the researcher's ability to consider the complexities that can occur in a study and develop a plan for how to handle them. To achieve credibility, the methods and findings must be inseparable. Thus, the credibility of a study is related to the entire design process.

Questions considered during the present study to increase credibility included:

- How does the method align with the research question?
- How do I understand and engage with patterns that I saw in the data?
- How can I interpret and make sense of the data so that my assumptions and biases are challenged? (Ravitch, 2016)

To ensure credibility, strategies such as triangulation, providing clear descriptions and having an external auditor can help. This was ensured in the present thesis by using an interview guide covering topics that should be included in the interviews. Probes were also used during the interviews to obtain more detailed information (Shenton, 2004). Research is considered credible when the interpretation of participants' experiences are so well described that other people with the same experiences can immediately recognise the results (Krefting, 1991). Since the researcher in this study was the main instrument during the entire research process, it was important to reflect on one's impact (Shenton, 2004). This can be covered under the concept of reflexivity, which will be described in the 3.6.5 section. The PhD candidate did not go back to the participants for member checking. However, since the transcription was conducted shortly after the interviews, disclosed concepts could be asked about in the next interview. The analysis was performed with the Swedish speaking supervisors, who relied on transcriptions in Swedish. The analysis was then discussed in English with all of the supervisors.

3.6.2 Transferability

Transferability refers to how well the research findings apply to other environments. Clear descriptions of the data collection process, analysis and context can enable readers to transfer study results to other settings (Krefting, 1991).

Transferability is comparable to external validity or generalizability in quantitative research. However, the goal of qualitative research is not to make a true statement or generalise the result to other settings (Ravitch, 2016). Instead, it aims to develop descriptive and context-related statements (Guba, 1981) and determine how these can be transferred to a broader context while simultaneously keeping with the phenomenon (Ravitch, 2016). This can be addressed if the research is repeated in a similar population and context and the results turn out to be similar. Apart from clear descriptions of the process, this can be achieved by overlapping methods for the same phenomena or making comparisons with other contexts (Ravitch, 2016; Shenton, 2004). To achieve transferability, the questions that the PhD candidate considered while conducting this study (Ravitch, 2016) included:

- How was the context described?

- Was enough contextual data provided so the readers can contextualise the findings?
- How were the setting and the participants described?

In qualitative research, it is up to the readers to assess and adopt other contexts; however, this must be based on good descriptions (Krefting, 1991).

3.6.3 Dependability

Dependability refers to the stability of the collected data. Notably, data are considered dependable if the results are consistent with the inquiry if it were to be replaced with the same subjects or in a similar context (Krefting, 1991; Ravitch, 2016). Dependability is comparable to reliability in quantitative research. Research can be described as dependable if it is consistent and stable over time. The argument for using a chosen method must be consistent with the research question and concepts fundamental to the study. Strategies used to achieve dependability mainly include triangulation and with a clearly described plan that can confirm that the method is an appropriate technique for the collected data (Ravitch, 2016). In this thesis, a modified version of triangulation was used since the phenomenon was approached and described from three different perspectives. Questions that were useful to consider when writing included:

- Why was this research method chosen?
- Is this an appropriate method for answering the research questions?
- What were the challenges related to the study's design, data collection, and data analysis processes? (Ravitch, 2016)

3.6.4 Confirmability

Confirmability ensures that results are derived from the study participants rather than from the experiences of the researcher. This is comparable to objectivity in quantitative research (Shenton, 2004). However, qualitative researchers do not claim to be objective (Guba, 1981). Such researchers do not seek objectivity but aim to confirm their findings instead. To demonstrate the confirmability of an interpretation, the researcher must acknowledge and explore ways of mapping our prejudices and assumptions and mediating them entirely. This is an extension of the reflexivity process (Ravitch, 2016). Triangulation can also ensure that the results of a study are derived from the participants and not the characteristics of the researcher (Krefting, 1991). Describing the same phenomena using different methods is defined as triangulation (Krefting, 1991; Shenton, 2004). However, since the present study was conducted using different interview methods in different populations, a modified version of triangulation was used to describe and understand their perceptions and experiences about the same phenomenon.

3.6.5 Reflexivity

The researcher is often engaged and serves as the main instrument in qualitative research throughout the entire research process. Therefore, reflexivity is another essential concept in qualitative research (Finlay, 2002). Reflexivity is defined by Berger (2015, p. 220) as "the process of continual internal dialogue and critical self-evaluation of the researcher's positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome" (p. 220). However, reflexivity suggests that researchers should be aware (in a thoughtful and mindful way) of evaluating one's positionality impacts on the data.

This leads to self-criticism towards the phenomenon. According to Finlay (2002), there are different variants of reflexivity: introspection, intersubjective reflection, mutual collaboration, social critique and discursive deconstruction. Among the variants of reflexivity, there are different ways to reflect. The choice of a reflexivity variant mainly depends on the methodology, aim and focus of the research. A combination of variants can also be used. First, “reflexivity as introspection” focuses on the value of self-dialogue during the research process and is based on the researcher’s reflections, feelings and thoughts. The researcher’s data, experiences and the meaning of the studied phenomenon are presented and this reflection can be used as primary data. Second, “reflexivity as intersubjective” is described as the meaning that arises between participants during meetings and the focus is on yourself in relation to others. The third form of reflexivity is defined by Finlay (2002) as “reflexivity as mutual collaboration”, in which the participants become co-researchers and vice versa, while the goal is to engage in a mutually reflective dialogue. The fourth reflexivity is “reflexivity as social critique”, which focuses on imbalances between the researcher and the participants in terms of social position, gender or race and how these imbalances are managed. The last variant of reflexivity is “reflexivity as discursive deconstruction”, which considers the use of language and the fact that there is always more than one meaning in language (Finlay, 2002).

To reflect and become aware of one’s influence on the data, various methods can be used. A summary of the methods used in this study is provided in Table 8. Notably, many of the methods overlap with each other. Making use of notes, memos, research journals and research audits has been recommended by qualitative researchers. However, according to Glesne and Peshkin (1992), it might be crucial to make use of notes. Nevertheless, it is recommended to do it continuously. Writing down ideas when they occur can be considered the start of data analysis and writing, which can furthermore stimulate ideas. According to Maxwell (2009), memos can “convert thoughts into a form that allows examination and further manipulation” (p. 11). Furthermore, making these notes and memos available for readers can help them evaluate the findings. The PhD candidate wrote notes and memos throughout the entire research process, especially during data collection and analysis. These memos and notes primarily consisted of thoughts, ideas, questions and feelings that arose. Furthermore, summaries were written after each interview. The summaries helped to reflect on the interview technique as well as the impression and imprint that the PhD candidate obtained during the interviews. The main purpose of the memos, notes and summaries was to help the researcher become aware of her own position and to be self-critical regarding the progress of the work in relation to the participants and aim of the study (Watt, 2007). The memos were often informally written in Swedish by hand within a notebook. Furthermore, the notes provided reflections on the interview technique and were often written down during data transcription. In particular, these notes were used in discussions with supervisors and to change the interview technique used. Furthermore, the PhD candidate had the opportunity to conduct two of the focus group interviews with one of her supervisors (EC), which further facilitated the comparison of interview styles and reflection on her own techniques. The time between interviews was also considered important for reflecting and transcribing the data. Certain memos, notes and summaries were translated and are presented in Appendices 13–15.

As a researcher, having existing knowledge about the context and research area can be both a disadvantage and an advantage as long as it does not affect the analysis and result (Catanzaro, 1988). Furthermore, reflexivity also includes what has been called “baggage” by Hsiung (2008), which refers to the researcher’s “personal characteristics such as gender, race, affiliation, age, sexual orientation, immigration, status, personal experiences, linguistic tradition, beliefs, biases, preferences, theoretical, political and ideological stances and emotional responses to participants” (Berger, 2015, p. 220). However, the extent to which researchers’ experiences should be highlighted in the text is often questioned (Finlay, 2002). A short description of the author’s pre-understanding related to the research topic and her working experiences were provided in the preface of this thesis. This pre-understanding was questioned, considered and discussed with her supervisors throughout the entire research process, especially during the data collection and analysis phases. During the data collection phase, it was challenging to change from the perspective of a clinical nurse to that of a PhD candidate conducting interviews within the vascular field.

Table 12 Variants of reflexivity and strategies used in the present study.

Variants of reflexivity	Strategies
Reflexivity as introspection	○ Memos ○ Summaries (interviews, supervision) ○ Discussions ○ Reflections ○ Transcribing the interviews
Reflexivity as intersubjective	○ Summaries from the interviews ○ Reflections on the interview technique
Reflexivity as mutual collaboration	○ Interview technique with probes
Reflexivity as social critique	○ Discussions ○ Supervision and feedback on the interview technique
Reflexivity as discursive	○ Transcribing the interviews in Swedish

3.7 Ethics

Research on health services relies on ethical principles to ensure that the involved participants are treated fairly and that there is a balance between risks and benefits (Mikesell et al., 2013). A principle can be explained as a general rule that can be applied to many particular cases and serves a standard of reference (Tangwa, 2009). The existing ethical guidelines for research were developed after the Second World War and are based on the Nuremberg Code. This code includes the following criteria:

- The researcher must inform subjects about the study.
- Research must be for the good of society.
- Research must be based on animal experiments, if possible.
- Research must try to avoid injury to research subjects.
- The researcher must be qualified to conduct research.
- Subjects or the researcher can stop the study if problems occur.

  (Nieswiadomy, 2008, p. 29).

After 1947, other ethical codes were developed. For example, the World Medical Association adopted the Declaration of Helsinki in 1964 and its most recent update occurred in the year 2000. Based on this declaration, ethical committees or institutional review boards should provide advice, guidance and permission for studies (Rickham, 1964). The present study was approved by the Hong Kong Polytechnic University Research Ethics Committee (HSEARS20170608001) and by the Central Ethical Review Board in Lund, Sweden (ref 2010/239, 2017/346) (see Appendices 16–18). This was done to fulfil the requirements of the Council for the International Organization of Medical Sciences (CIOMS) for conducting research on humans. The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research has the goal of achieving basic ethical principles for research involving human participants (Tangwa, 2009). The three ethical principles outlined in the Belmont report (US Department of Health & Human Services, 1979) are:

- Respect for persons: research subjects should have autonomy and self-determination.
- Beneficence: research subjects should be protected from harm.
- Justice: research subjects should receive fair treatment
(Nieswiadomy, 2008, p. 29)

The word "autonomy" comes from the two Greek words "*autos*" and "*nomos*", where the word "*autos*" means "self" and "*nomos*" means "rules". Therefore, the principle refers both to the freedom of each individual to act but also the obligation of others to respect that freedom (Tangwa, 2009). Beneficence means doing good, while non-maleficence refers to avoiding harm. Based on these principles, researchers are required to maximise the benefits and minimise the harm for the participants in their studies (Mikesell et al., 2013; Tangwa, 2009). The principle of justice refers to fairness or entitlement and requires that "equals be treated equally and un-equals unequally" (Tangwa, 2009, p. 5). The general moral idea for justice is "Do unto others as you would have them do unto you if you were in their place and they in yours". In terms of Swedish law, no ethical approval is required for interviews with health care professionals. An additional application to interview the partners was sent under the already approved ethical permission for interviews with the men (Dnr 2010/239).

Permission to conduct the study was obtained from the heads of the clinical departments. The participants were informed of the nature of the study and its purpose, which were indicated on the information sheet (see Appendices 1, 2, 4, 5, 8 and 9). Written and verbal information was provided to the participants before their interviews. Informed consent was given by the participants before the interviews started (see Appendices 3 and 6). The purpose of obtaining informed consent was to provide the participants with a full understanding of the study before the study began, while the consent form ensured that the participants' rights are protected. A consent form should include the following:

- The researcher is identified with credentials presented.
- The subject selection process is described.
- Purpose of the study is described.
- Study procedures are discussed.
- Potential risks are discussed.
- Potential benefits are described.
- Compensation (if any) is discussed.
- Alternative procedures (if any) are disclosed.
- Anonymity or confidentiality is assured.
- Rights to refuse to participate or to withdraw from the study without penalty are assured.
- Offer to answer all questions posed.
- The means of obtaining the study results are presented.

(Nieswiadomy, 2008, p. 31)

Participation in the present study was voluntary and each individual could withdraw at any time (De Roubaix, 2011; Tangwa, 2009). To ensure the autonomy of the participants, the PhD candidate did not make the initial contact with participants. Instead, this was done via a written invitation that the participants could respond to through either email, mail or phone.

Privacy and confidentiality were guaranteed since the interviews were held in a private room in a hospital or a location chosen by the participants. All participant names were coded as numbers during the analysis process to ensure confidentiality. Health care professionals in the focus group interviews were reminded to keep the conversations during interviews confidential. A list of the real names was kept separately from the data. Data will be stored under lock and key for safety. All computer files related to the study are stored under the protection of a password. After 10 years, the data will be destroyed.

During a few of the interviews, some participants became anxious and or cried. The PhD candidate has 12 years of nursing experience and felt that she was able to provide the participants with support and appropriate consultations. In some of the interviews where the participants became worried or anxious, they were reminded that we could continue with the interviews at another time; however, they all insisted on continuing. The PhD candidate did a few follow-up phone calls a couple of days after the interviews with some worried participants. This was to ensure that they recovered well and were feeling good after the interviews. The angiologist and vascular surgeon were contacted in some cases and asked to follow up with some of the participants due to their worries, questions and enlarged AAA sizes. Notes were then made by surgeons or angiologists in medical records to further follow up with these participants. Furthermore, the telephone number of the screening service at the hospital's vascular clinic was given to some participants if they had many practical questions. The goal during all of the interviews was to achieve a well-balanced approach of awareness by not causing any harm, which was achieved in most of the interviews.

3.8 Chapter summary

The methodology chapter was presented in line with a post-positivist paradigm and followed by a short description of the QD methodology. Emphasis was placed on the QCS method used to conduct this study. This chapter described the context of the case followed by the participant recruitment, data collection and data analysis strategies. The concepts used to describe rigour, credibility, transferability, dependability and confirmability were outlined and ethical considerations were also presented. The next chapter (Chapter 4) describes the results of the present study.

CHAPTER FOUR

RESULTS

4.1 Introduction to the results chapter

This chapter presents the findings of the QCS "Perspectives of a screening-detected AAA", which was conducted in Sweden. The findings are presented under four subsections. Firstly, the chapter presents the within analysis of the embedded unit on the partners' experiences of living with men that have a screening-detected AAA. Secondly, a within analysis of the men's experiences of living with the awareness of having a screening-detected AAA will be presented. Thirdly, a descriptive analysis of health care professionals' experiences in screening and caring for participants with a screening-detected AAA is presented. Lastly, a cross-analysis illustrating the contrasts between the men's and the partners' perspectives on living with a screening-detected-AAA is presented. This subsection is demonstrated as "The screening surveillance journey" and also presents the health care professionals' perceptions and experiences of caring for men who have an AAA and their partners. A summary concludes the chapter.

4.2 Demographic characteristics

The analysis of the partners' experiences of living with a man that has a screening-detected AAA was derived from 21 interviews with partners. All of the partners were women with a mean age of 67 years, ranging from 57 to 77 years. Out of the 21 women, 1 was born outside Sweden. The analysis of men's experiences of living with a screening-detected AAA was based on 25 interviews. The mean age of the men was 69 years, ranging from 65 to 72. In this study, the partners were consecutively coded with numbers ranging from 1 to 21, while the men were consecutively coded with numbers ranging from 100 to 125 to maintain the anonymity of the participants. Code lists were kept separately from the name of the participants. Health care professionals that participated in the interviews had health care working experience ranging from 5 to 33 years. Both RNs and medical physicians participated in the interviews. The majority of participants were female and the interviews involved an average of three professionals. The interviews were consecutively coded from I to V. The next subsection will present the within analysis of the partners' experiences.

4.3 Introduction to partners' experiences and perspectives on living with a man that has a screening-detected AAA

The first subsection of the results chapter described perspectives of the partners' experiences living with a man that has a screening-detected AAA. The partners explained how they lived with recurrent and widespread worries that encompassed three aspects of life, which were divided into three categories: 1) *Experiencing the unexpected*; 2) *Being reminded of fragility*; 3) *Balancing a changing relationship.* The category "Experiencing the unexpected" consists of two subcategories: 1) *Shock and emotional reactions* and 2) *Peripheral to first-hand information.* The category "Being reminded of fragility" is made up of three subcategories: 1) *Reminders during daily activities*; 2) *Waiting in uncertainty*; 3) *Ambivalent feelings about surgical treatment.* Lastly, the third category, "Balancing a changing relationship", consists of three subcategories: 1) *Supporting a healthy lifestyle*; 2) *Protecting role*; 3) *Preparing for the worst.*

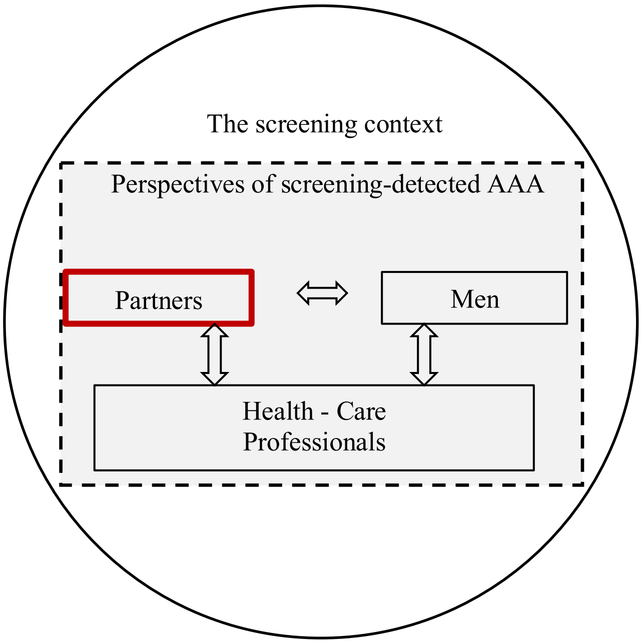

Figure 7 Illustration of the case with the three embedded units. This subsection will present the inductive within analysis of the embedded unit consisting of the partners' experiences of living with men who have a screening-detected AAA (highlighted in red).

4.3.1 Experiencing the unexpected

Partners expressed an initial process of resistance to the diagnosis of AAA. Simultaneously, they were satisfied that the health care system provided the screening examination for their partners. This can be demonstrated in two subcategories: a) *shock and emotional reactions*; b) *peripheral to first-hand information*.

Shock and emotional reactions

Before the first U/S examination, partners expressed how they tried to mentally prepare themselves for the potential risks that their partner could suffer from an aneurysm. Some doubted that their partner was at risk, implying that they had a healthy lifestyle. Nevertheless, the partners received the screening results with feelings of shock, surprise and sadness. They could not believe that it was true and considered the message to be inconceivable. Furthermore, partners of men with comorbidities felt resentment and thought it was unfair that they should suffer from an additional disease. This implies that they already had enough negative experiences with illnesses.

I was sad and in shock and thought it was unfair that he also got this (AAA) diagnosis against him (9).

Despite the adverse emotional reactions, the partners were pleased to be aware of the aneurysm at an early stage and were relieved about surveillance via regular U/S follow-ups. Notably, this means that the partners trusted the health care system and its professionals while expecting and hoping that something could be done before a rupture of the aneurysm occurs. On the other hand, this awareness and surveillance with follow-ups also impacted the partners' lives, as expressed in the following quotation:

I am worried but simultaneously pleased that they have him under control (1).

Peripheral to first-hand information

Notably, AAA diagnoses led to unanswered questions for the partners. Concerns and questions regarding the reasons for developing the disease included the risk factors associated with the AAA, the progression of the AAA and genetic predisposition were common concerns. Moreover, the partners expressed a lack of information about lifestyle and its impact on AAA.

As a relative, you would like to know what it (AAA) is, its progress, what can happen and if you can do something to prevent it from growing; for example, through lifestyle changes or something else (5).

The partners experienced stress since they did not understand why their diagnosed partner had to wait for surgery and considered this to be strange and unclear. Some of them even believed that the health care system was purposely waiting for a rupture before performing the surgery. Furthermore, they were unaware of the reasons why their diagnosed partner did not undergo a proper medical examination.

But I wonder why they [health care professionals] do not operate when they know about it (AAA). Why do they need to wait until the AAA becomes 50 mm or whatever the limit is? (10).

The information that reached the partners was described as "secondary information", which was first provided by health care professionals to the men and then from the men to their partners. Furthermore, the information that partners received from their men after U/S examinations was often described as superficial. In general, they were only informed about the size of the AAA, the scheduled time for the next examination and how their men were supposed to continue living their normal everyday life. The partners perceived that the men either had no more knowledge than they did or that they did not want to discuss it. When the partners felt that they lacked knowledge about the aneurysm and its progress, they blamed themselves for not being interested or curious enough to search for information on the internet.

The information I get through my husband is scant and then I do not know. I do hope that I have not been a bad listener (18).

The partners seldom accompanied the men to the screening examinations and thus did not receive information directly from the health care professionals. However, those joining the screening examination were usually waiting outside while the male partners were undergoing the U/S examination. Some of the partners voiced the idea of inviting a relative to join at least one of the consultations so that both could receive the same information from the health care professionals.

But I think it would probably be good to introduce some routine, at least during some of the consultations, where relatives could participate and discuss what you can do in this situation, what it means and what you can think of and how to behave (5).

Apart from reconsidering the value of accompanying their men to the next U/S examination, some partners took the initiative to obtain information about the disease from the internet. However, most of them thought that looking for information themselves caused more worries since they became confused about the relevant information they should be seeking.

I do not want to search for information on Google because there is information I will not understand and it will become problematic for me (13).

4.3.2 Being reminded of fragility

The awareness of having an AAA reminded partners of the fragility of life during daily activities or in certain circumstances, which influenced their lives to varying degrees. How the AAA affected their lives was often due to previous experiences with AAAs, such as work experiences or cases where another relative had suffered from the same disease. If the partners had a fatalistic attitude or were not afraid of dying, this helped them to accept the diagnosis and not let it influence their daily lives. Being reminded of fragility is described according to three subcategories: a) *reminders during daily activities*; b) *waiting in uncertainty*; c*) ambivalent feelings about surgical treatment*.

Reminders during daily activities

The partners were reminded of the AAA when their diagnosed partner went out by themselves because they were afraid someone would call and tell them about a rupture or death due to a rupture. There were also descriptions of how the partners began to look for their diagnosed partner as soon as they did not know where they were. The partners explained how they became worried when their men got upset or angry because they were afraid it might cause a rupture. Additionally, they were worried when their men were driving because a rupture in the car would cause their own deaths and risk the lives of others.

Furthermore, the partners also expressed that it was essential for them that their men did not carry heavy objects anymore. Therefore, partners took over gardening and other heavy duties, sometimes this was against their diagnosed partner's will. Avoiding lifting heavy objects was also mentioned as a restriction by health care professionals. However, it was confusing and unclear for the partners to know exactly what the health care professionals defined as too heavy or what kind of carrying their men were allowed to do. In addition to lifting heavy objects, doing other physical activities was often a source of worries.

But then you wonder, what is heavy? What is the limit?...yesterday we moved a TV, and then suddenly I was thinking "Oops, that was heavy—does it count?" But then you think it might not count as heavy. It depends, but then you don't know the limit for what is heavy or not (10).

Since the partners believed that ruptures were not always related to symptoms of extreme abdominal pain, they explained that they checked if their men were breathing and alive during the night, as stated by one of the partners.

During the night, I think of it almost every night. Is he breathing or not? (crying) (9).

If the men suffered from comorbidities, partners had difficulty in distinguishing their worries and were often concerned about their health in general. Additionally, the partners of men with comorbidities described how their concern for the AAA became worse if their diagnosed partner experienced deterioration in another health condition. This is expressed below:

Actually, it is difficult for me to separate what I am thinking of because his health generally makes me worry a lot. But if it is just that (AAA) or if he should have another heart attack, I cannot say—but his health has a great impact on me (20).

It was also revealed that the AAAs imposed limitations on partners' lives. When making plans for future social activities with family and friends, they were sometimes reminded of the AAAs and asked themselves whether they dared to make plans for the future. Furthermore, many mentioned that travelling abroad posed a risk since they wanted to be close to a large hospital near their home, where aneurysms could be taken care of. In addition to being far from Sweden, not being familiar with another language, health care system or culture also caused worries. The participants perceived that health care professionals insisted that couples could travel and continue living a normal life. However, this was often taken as empty words since they felt unsure about whether travelling abroad was safe. Furthermore, partners also considered flying as a risk for rupture. Some of the partners had tried to get clarification from both their insurance company and from the International SOS about expected support and care if something were to happen while abroad.

But when it comes to travelling, we have started to reconsider—do we dare? Maybe we do not dare to travel. Maybe we should stay in Sweden (laughing) until this is over, until he has been through a surgery for the AAA, finally, hopefully (10).

Waiting in uncertainty

The partners expressed that they could not do anything about the AAA except wait for an uncertain outcome. They explained how they waited for the next U/S examination, surgery or rupture (with or without a fatal outcome). Many of the partners knew that the AAA diameter could not decrease and that the AAA would not disappear on its own. Therefore, they were relieved when the AAA did not increase in diameter between follow-up examinations.

It was a relief that it (AAA) has not increased the last few times. I am a little calmer! (5)

When the men's AAA increased in diameter between follow-ups, this became a threat for the partners, caused more worries and led the partners to think about the AAA more frequently. Concerns arose that it would grow too fast and that the health care system would lose control over it. The partners found the time between follow-ups to be too long and wished that their diagnosed partner could have more frequent follow-ups with U/S examinations of the aorta. They described how they tried to estimate how much the AAA increased in size between follow-ups since they knew that the aorta was not very big and did not have the potential to grow too much; therefore, a few millimetres could have devastating effects. Moreover, partners often described AAA as a fatal disease. Some of the partners implied that they had an invisible line in their mind that seemed to be related to a diameter of 55 mm, which many knew was the recommended size for surgery. When the AAA came closer to that size, their worries increased.

But since it (AAA) has increased in diameter and it is close to surgery, there is just a little difference regarding whether they should operate on him or not; therefore, I have become more worried because there might be a line and when it comes close to that line, the risk for rupture increases—and he is so close to that now (6).

Ambivalent feelings about surgical treatment

In general, surgery was recommended as the only solution to dispose of the AAA and its negative impacts so that partners could continue their lives without thinking of aneurysms anymore, as described in the following quotation:

Yes, that is what I want for him (to have surgery), so I don't have to go around and be worried all the time. We don't know how much it (AAA) grows. It has grown much in just a short time. And why does it grow? (2)

The partners felt that they trusted the vascular surgeons to perform the AAA surgery and were not worried about that. Simultaneously, unpleasant feelings about potential surgical treatment were expressed. Some of the men suffered from other comorbidities and the partners were worried that their men would not be able to receive the surgery. Furthermore, they had previously heard that it was a complicated and dangerous surgical procedure undergo. If surgery was necessary, they expressed how they needed to be mentally prepared for a fatal outcome. However, if the choice was to be made between rupture and high-risk surgery, the latter was considered necessary.

But if they need to operate on him—if you have to choose between rupture and surgery to not have a rupture or minimise the risk for rupture—then you do not have a choice if they (health care professionals) see it as necessary. Then you need to prepare yourself for two outcomes (death or survival). And it is difficult to know how one should feel. It is very difficult to know in advance (5).

4.3.3 Balancing a changing relationship

The diagnosis of AAA made the partners emotionally involved in the disease, its process and the well-being of their diagnosed partner. Their sincere desire was that their diagnosed partner would survive the aneurysm. Therefore, it was important for the partners to be supportive and present throughout the screening pathway despite challenges to their relationship, as expressed in the following aspects: a) *supporting a healthy lifestyle,* b) *protecting role* and c) *preparing for the worst*.

Supporting a healthy lifestyle

It was important for the partners to know what they could do to prevent the growth of the AAA. Therefore, it was essential to adapt to (and maintain) a healthy lifestyle, which was demonstrated as a minimum requirement for a healthier future. The partners also tried to encourage their diagnosed partners to be more physically active, quit smoking and lose weight. The partners said that they tried to prepare a variety of meals including vegetables. However, some of the partners found that their diagnosed partner did not take enough responsibility for their own lifestyle and health, which caused feelings of frustration, anger and worry. They were also worried about their common future. Simultaneously, the partners were aware of the difficulties they could face in changing their lifestyles and had to accept their men's life choices.

…I become angry because he did not quit smoking, is physically inactive and a little overweight. I think he should take care of himself…that he doesn't want to do anything about it is a factor for uncertainty for me and my life. I have stopped

talking about it... I gave up. He has to do what he thinks is good and I will try to accept it (20).

Protecting role

The partners said that they tried to protect their men from any negative impact that the AAA had on their partner or themselves. It was emphasised that the partners always tried to show that they cared about their diagnosed partner and their health by asking them how they were feeling, as illustrated in the following quotation:

I think it is very difficult, hmm. I ask him how he is and how he feels and so on, but I always get to hear that it is bad. I ask anyway, to show that I care for him. We never talk, or how can I say it… I never mention the disease (AAA) or his heart—no, I do not. Actually, I feel inadequate (9).

The partners further described how they seldom talked about the aneurysm with their diagnosed partner. Those with previous knowledge about AAAs wanted to protect their diagnosed partner from further worries and thus kept their own experiences and worries to themselves.

Other partners stated that their men changed after their AAA diagnosis. They mentioned that they were not that happy anymore. One partner mentioned that her husband suffered from depression after the diagnosis, while others described how their husbands became restless, afraid and reserved, as described in the quotation below:

He has become quiet and reserved. He used to be a happy person before the (AAA) diagnosis (11).

The changes to prevent the men sometimes also limited them from doing what they had done previously, which also affected the partners, who tried to improve the mood. Furthermore, the men's moods affected their partners and the way they handled the diagnosis in their daily lives. Partners explained how difficult it was to always be the happy and strong one in the relationship. Some even worried about what would happen to their diagnosed partner if they passed away before them.

Preparing for the worst

During the interviews, it was revealed that thinking about aneurysm rupture was related to stress for the partners. Moreover, the partners were worried that they might not be close enough to notice or be able to help save their diagnosed partner in the event of a rupture.

I am just thinking about what I can do if it happens (rupture), how to get help quickly enough and what I can do before he dies and comes to the hospital. Those are some of my thoughts and concerns. How I can get help and what I can do (6).

Some partners had made detailed plans of whom to contact and what to say if something happened, while this was unclear for others. However, it was clear that survival could change in a matter of minutes. Thus, many partners wanted to know more about the early signs of a rupture.

AAAs served as a reminder that it was important for the couple to share information on topics such as financial matters or other household-related duties that one of them previously had been more responsible for. Some of the partners even described how they made financial plans and savings in case they would be left alone. It also became clear and important to spend time together as a couple.

4.3.4 Summary of the partner's perspectives

This sub-section of the results presented the partners' perspectives of living men having a screening-detected AAAs. These perspectives were captured under three categories: 1) *Experiencing the unexpected;* 2) *Being reminded of fragility;* 3) *Balancing a changing relationship*. The results indicate that the partners were thankful for the invitation to the aortic screening and outline how they mentally prepared themselves for a potential diagnosis. Despite the preparation, they were still shocked at the diagnosis and expressed a range of emotions. Furthermore, the considered the information they received to superficial, which led to concerns that impacted on their lives. Surgery was seen as the only solution to get rid of the AAA and return to a normal life. Additionally, the partners were unclear about why the men had to wait for an operation. Moreover, both waiting for surgical treatment and the operation itself caused worries among the partners. During the screening surveillance, the partners attempted to support the men and encouraged them to live a healthy life, in order to minimise the risk of AAA expansion. The partners balanced their lives, attempting to support their men in the daily life, whilst preparing themselves for a rupture or surgical treatment and at the same time balancing emotional impacts.

4.4 Introduction to men’s experiences and perspectives on living with a screening-detected abdominal aortic aneurysm

In this subsection of the results chapter, the men’s own experiences of living with an aneurysm detected through screening will be presented. The analysis is presented under the three categories *Experiencing the unexpected*, *Being reminded of fragility* and *Balancing a changing relationship*, which were common between partners and men. The findings are based on material from 25 interviews with men (Table 5) with a screening-detected AAA.

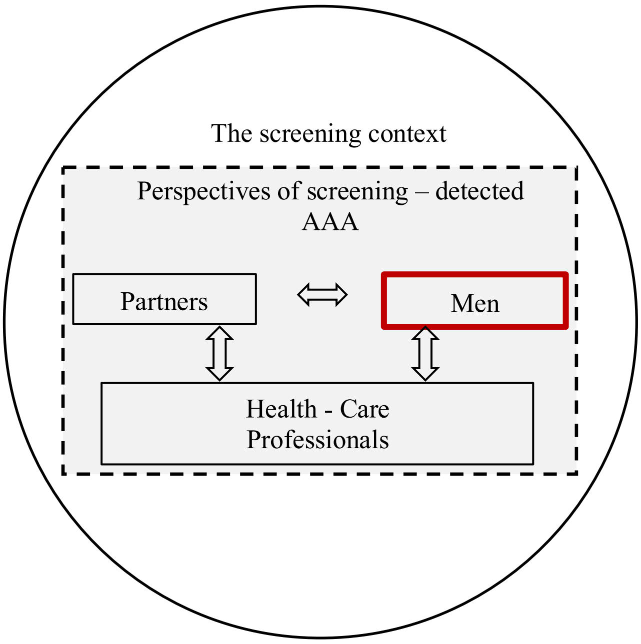

Figure 8 Illustration of the case with a focus on the men’s experiences with a screening-detected AAA (highlighted in red).

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4.4.1 Experiencing the unexpected

For the diagnosed men, experiencing the unexpected meant being surprised by the AAA diagnosis disclosed at the first screening examination. Furthermore, they looked for information to understand why and how this could happen to them. The men who participated in the interviews expressed that they were happy and thankful for the invitation to a screening examination of their aorta. They noted that it was a really good service from the health care service and were impressed that they could provide the service during a difficult time with financial short-comings and a shortage of staff. Since the invitations were addressed from the health care service, they were interpreted as a reliable source and it seemed that none of the men hesitated to join the U/S examination or considered it to be a voluntary offer. The men just marked the date for the U/S in their calendars and did not think about it any further.

Once at the screening, messages about AAA diagnosis were received with varying responses. There were descriptions of being pleased to be updated and aware of their aneurysms. Some men also described that they did not react in any special way. Some just accepted their fate. For others, the diagnosis meant that they already lived beyond their expected lifespan and were not surprised at all that they also suffered from an AAA. Expressions such as “Everything affects me” were stated. Additionally, some stated, “If I don’t suffer from one disease, another diagnosis hits me”. One man related his diagnosis to a song that he used to sing.

And then he sings like this, “If you see me coming, then it’s best you step aside. My right hand is steel and the left is iron So, if one hand does not hit you, then the other hand does. So it is. You see, that’s how I feel. I have my heart problems (pointing to his heart) that is one fist, and then this (the AAA). So, if this doesn’t kill me, then the other one does (109).

Although there were also descriptions of being surprised and baffled when the nurse told them about the diagnosis. Some were surprised that they belonged to a small group of affected men, especially since it was stated in the invitation that the percentage suffering from AAAs was low. The men expressed what they had in their mind when arriving at the screening: “This does not happen to me.”

But you do not expect it, that I—I mean, the likelihood of being one of those who actually suffer is very low. So, you think, “It does not happen to me”, but it did (113).

What they actually wanted to hear was that “Everything was OK with their aortas and health status and that there is no further need for follow-ups.” They expressed that the best result for the examination would be that it was completely unnecessary.

Additionally, the men expressed that they became shaky and dazed when they heard the nurse telling them about the AAA. One man mentioned that he fainted and he was so disappointed that his retirement started in such a negative way since he had expected something entirely different.

There were various important aspects related to how the men continued to live with their diagnosis. Some mentioned that time was required to process the message. Other mentioned that the way they received the message from the nurse at the screening was important, noting that the nurse gave them their diagnosis in a confident and trustful way, which made them calm. Another important aspect related to how they accepted the diagnosis was the information they received and their understanding of the information provided. They described how they received both written and oral information regarding their AAA diagnosis from the nurses at the screening clinic. Their reactions to the information varied from being satisfied and pleased to feeling that some information was forgotten or not mentioned by the health care professionals.

Regardless of the information given, it remained unclear to some men what an AAA was and the reasons for getting it. An AAA was described as something that grew or clogged up in their veins. However, some men thought they have had it since they were born, while others guessed that there was a connection with other hernias in their body (e.g., groin or umbilical hernias).

It can be explained like this: it is the veins that are so stretched that a change happens. In some ways, it is like a hose getting older and almost cracking, but this one (the aneurysm) does not crack—it only stretches, that is what I think. But I have also had an umbilical hernia, so I suppose there is a connection with different hernias, but I do not know (122).

Furthermore, the men assumed they had used their bodies incorrectly by carrying heavy loads or overworking themselves. Others mentioned that it could be generic or due to their smoking habits. However, all diagnosed men knew that it was something that happened in their vascular system, even if it was unclear for some whether it was in their veins or arteries.

Those men that expressed that the information they received was scant and that they needed more detailed, in-depth and personalised information. They wanted to know what they could expect, what caused the progression of the AAA, what kind of surgical treatment they could expect and the risks of having an operation. One belief about not receiving more information was that they thought there was a lack of general knowledge and evidence about AAA, which made it impossible for the health care professionals to inform them further. Furthermore, the men also noted that it was unnecessary to be informed about things that were irrelevant to them at the moment. They believed that more information would come along the way. For some, a lack of information was solved by looking up information on the internet. Some considered this a quick and easy way of looking up any information that they lacked.

There are some gaps in the information. But you can always look it up on the internet. I use my mobile phone to ask my question and I immediately have the answer (113).

Others noted that the information they were reading on the internet became more complex when the AAA expanded, which resulted in some becoming confused when reading information themselves. However, some men also highlighted that they were very satisfied with the information provided by health care professionals, implying that they had received enough information from them.

In the interviews with diagnosed men, they reiterated that they were aware of the need to be invited for new follow-ups. AAA size was also something that the men remembered from the examination. Furthermore, AAA size information was perceived and understood as the AAA being something that could be dangerous if it expanded, which could result in it starting to bleed. Based on their understanding, survival upon AAA rupture is a question of minutes and how close they are to a hospital. One man summarised the information about survival from a folder he received:

I got an information folder where I read that it (the AAA) could rupture and then it would take 5 minutes before it (life) is over (107).

This could cause stress since some men informed their partners that they should call the vascular out clinic in the event that they experience extreme abdominal pain. However, the opposite was also observed since some men accepted the diagnosis with ease.

Well, that is nothing to worry about. If it (aneurysm) bursts, it bursts. And if I am lucky, I might survive. But I do not believe in that (in survival) (111).

Regarding information about the impact of lifestyle on AAA progression, men mentioned that they were asked about their smoking habits at the screening. If they were smokers, they were asked to quit. However, few were informed about the connection between AAA progression and smoking or smoking being a cause of aneurysm development. However, some of the men drew their own conclusions, as shown in the following quote:

I can imagine that smoking weakens the walls of the vessels and if I quit smoking, the walls will improve, which would be an advantage—especially for the Chronic Obstructive pulmonary disease (COPD)—but maybe it also has some effects on the AAA. I can imagine that that is how it is (114).

Some men also received explanations from health care professionals about smoking not being good for their aneurysm; however, many of the men that continued to smoke doubted this information. In contrast, it was also highlighted that some men wanted further clear directions regarding smoking cessation, while others wished that the health care professionals would more or less force them to quit smoking and change their habits. They saw it as a good reason, and maybe the only one, for them to quit smoking. Except for smoking, no other information regarding lifestyle changes or their impact on AAA progression was given to the men.

4.4.2 Being reminded of fragility

Living with the knowledge of having an AAA impacted the men's lives in different ways and to varying degrees. It was a reminder of their fragility and meant that they should avoid strenuous activities. Moreover, it provided an awareness of the finality of life. This awareness made them consider the potential options for AAA treatment.

In the interviews, the men expressed that they were reminded of their AAA when carrying heavy things or performing other heavy physical work, such as weightlifting at the gym, gardening or chopping firewood. Some found their own solutions to avoid lifting or carrying heavy things (e.g., tools, machines and other devices). Other men noted that they purchased battery-powered bikes, while others handed strenuous work over to others. At the gym, the men avoided heavy weights, especially for the abdominal area, and did cardio fitness instead. Furthermore, other situations when the men were reminded of their AAA was when they were in big social groups since they were afraid that someone might accidentally bump into their stomach or back. Stomach aches also reminded them of their AAAs. Descriptions of feeling their pulse and imagining it was the AAA when sleeping or lying on their stomach was also stated during the interviews.

I could feel it clearly since I sleep on my stomach. I really felt how the pulse went tik tok. So real. So I visualised that it (the AAA) might be too narrow. So I thought, "What the hell, it may have started to clog even more and the aneurysm might start to swell." (109)

There were also descriptions of being reminded of the AAA at funerals since it reminded them of their own death. Some men were reminded of their aneurysm when it was time for follow-ups or if they heard about others that also suffered from an AAA.

One reason that the men only thought about the AAA when it was time for follow-ups was that they trusted the health care service. Both the medical assessment and the health care professionals had control of their surveillance and the progression of the AAA. The men completely relied on the follow-ups, which meant that they could continue to live their lives as usual. This was important for continuing with their old hobbies and the lives they had before the diagnosis; otherwise, their lives would be of low quality. One man stated that he was reconstructing his old house and made new travel plans. The men related the ability of the AAA to impact their lives on their personality, sense of self-trust and their upbringing. There was nothing the men could do to make their AAAs disappear. This was mentioned as a reason for simply letting go of thoughts regarding AAAs. The men could also drop thoughts about AAAs since they knew that everyone will die of something or because they knew that nothing could be done to make the AAA disappear. Furthermore, the men relied on their psychological abilities, which allowed them to handle the situation with ease.

I am a quite hard-headed person (laughter) and probably I do have a strong psyche as well. So what can I say, you should die from something (111).

Furthermore, since the men got the impression from professionals at the screening that their AAAs were slightly larger than the normal size, it did not seem too serious to them yet. Furthermore, the AAAs seldom affected them since no physical differences were felt in their bodies. This sentiment was expressed by one of the men.

Since I don't have any physical problems, I don't worry about it (AAA). I do not think about it. I mean there is nothing that hurts. It is not like having a toothache, which hurts all the time (101).

If the AAA grew, it did not make any difference to them. Nevertheless, some men expressed that it was strange to be waiting for their health to get worse before it got better; however, it was still a reassurance if the AAA was stable between follow-ups.

It comforted me a little that it had not grown, which is a good sign I think. But if it grows, then I might be worried again (113).

However, some men constantly thought about their AAA and wondered what will happen to them in the future. Some men noted that because of the diagnosis, they could not sleep due to nightmares. While their dreams were not always related to their AAA, this meant that they did not have good dreams since the AAA diagnosis. However, the men were happy every morning and they still woke up ready to face a new day. In the interviews, some men also expressed that they constantly had AAA on their minds and were anxious about it ending their lives. One man compared his situation to having a bomb inside his stomach, while another compared his aorta to a snake that had eaten an anaconda that was too big to fit inside.

It's not nice to live with the knowledge that you have this. It's like an internal bomb belt, huh... Yes, you get that feeling. And I'm not someone who would wear an explosive bomb belt (114).

When the AAA grew and it came closer to surgical treatment, ambivalent feelings were expressed. However, some noted that the progression of their AAA did not cause any worries and an eventual operation was not something they thought about. In contrast, other men noted that they were afraid and worried about a potential operation.

For example, men that were not bothered about a potential operation compared the aorta operation to other operations (e.g., orthopaedic operations) that they previously experienced and argued that their survival was somehow a guarantee for them also surviving an operation of the aorta.

But surgery is surgery and there are certain risks with that too. But if you can go through a knee operation you can go through an operation of an aortic aneurysm. That is how it is (104).

Additionally, other arguments for not worrying about an operation were that they had previously heard that it was an easy operation that involves entering the vascular system through the groin and inserting a net in the vascular system. Some further explained that they were hopeful and drew similarities to entering an aeroplane and the question of their survival being entirely in the hands of others.

On the other hand, some men had previously heard that the survival rate for this aortic operation was low. One man stated that mortality was related to poor surgical techniques, while others hoped that the techniques had developed further and would continue to do so until it was time for them to be operated on.

Moreover, some men had thoughtfully researched the survival statistics following aortic surgical treatment, found them scary and became more worried. These men asked and hoped for more information and had discussions with their surgeon about the operation and individual risks in detail. Some men also stated that they sometimes doubted the professionals working at the screening centre and whether the stories they told them were relevant and true. For them, it was unrealistic that they could get out of bed, have breakfast and return home the day after the surgery. This was seen as idealisation, as noted by one man.

I do not just want to survive the operation. I also want to feel good and have a good life afterwards (104).

Some men also mentioned that they needed to be realistic. If they were too old when it was time for an operation, they expressed that they would rather refrain from the surgical treatment.

4.4.3 Balancing a changing relationship

For some men, balancing a changing relationship meant showing their vulnerability and sharing their thoughts and emotions with their partners. On the other hand, they did not want to bother their partners, were stubborn and wanted to manage the changed life situation by themselves and not let the AAA impact their common lives.

The men honestly mentioned that they were responsible for their own health and lifestyle. However, they knew that both had an impact on their partners, which could lead to a constant guilty conscience towards their partners. Some men truly desired to change their habits (e.g., quit smoking) since certain habits hurt their partners.

It is my responsibility, no one else's. Not my therapist's, psychologist's, nor my wife's. She cannot take responsibility for me to stop smoking. I know, of course, that she is affected by me. I do not smoke indoors but she is affected by the knowledge of it. I am fully aware of this and yet I keep on (114).

However, some men expressed that they had previously, either individually or together with their partners, changed their lifestyles. However, this was often due to other diagnoses. Furthermore, some men noted that they were satisfied and wanted to continue with the lifestyle they had. For them and their partners, good food, drinks and sometimes a cigarette equated to a high QOL. This is described in the following quote.

My attitude with my wife has been that we should eat and live well for as long as we can. And that means—and has always meant—butter and cream in cooking. And there should always be a glass of wine with the food every day. So, when I told her, I said, "I got a new doctor, I've worn out two doctors (laughs)." So, when I got a younger female doctor, she said, "but then you should have this pill too." (Statins) (125)

However, some men also described that they did not believe that their lifestyle actually affected AAA progression and had thus made up their minds to continue living as they did before their diagnosis. Furthermore, men also expressed how they hid their lifestyles from their partners due to remorse and being fed up with nagging from their partners.

Notably, men sharing thoughts and emotions about AAAs with their partners could be a relief. However, the opposite was also stated. Some men avoided discussing AAAs with their partners and kept their thoughts and feelings to themselves. It was described that they did not find the AAA interesting enough and thus did not see the point of sharing. Moreover, many men also did not want to worry their families and relatives more than necessary. Since they did not like to discuss negative things in life (e.g., illness), they avoided it instead.

I never mention my misfortunes to my wife or my children. I sugar-coat it. I do not want to talk about that nonsense (102).

4.4.4 Summary of the men’s perspectives

This sub-section of the results described the men’s perspectives on having a screening-detected AAA, which were presented under the following categories: 1) *Experiencing the unexpected*; 2) *Being reminded of fragility*; 3) *Balancing a changing relationship*. The results indicate that the men were impressed by the screening service, disappointed that they were suffering from an AAA, and accepted their fate. The men were satisfied with the information they received, even if they still had questions regarding their diagnosis. However, they believed that more relevant information would come during the screening process or looked up information on the internet. The men trusted the health care professionals and felt safe under their control and surveillance. Although ambivalent feelings were described regarding surgical treatment, they expressed the desire for further detailed information about the operation. They attempted to follow the restrictions provided by the health care professionals and continued to live as normal while avoiding heavy physical activity. The men seldom changed their lifestyle due to the AAA diagnosis, even if the professionals asked them about their smoking habits. Although thoughts and emotions about the AAA diagnosis could be a relief to share with their partners, it was also seen as something negative that they did not want to share.

4.5 Introduction to health care professionals’ perspectives on screening-detected abdominal aortic aneurysms

The third subsection of the results chapter will present a manifest and deductive analysis of health care professionals’ perspectives on screening-detected AAAs. The analysis includes their views not only on the care and follow-ups for the men but also their descriptions of how they as health care professionals perceive the men’s reactions. The analysis is based on data from 14 health care professionals from four different screening centres in Sweden. The deductive manifest analysis is based on the following categories from previous subsections: “*Experiencing the unexpected*”, “*Being reminded of fragility*” *and* “*Balancing a changing relationship*”.

As stated in the methodology chapter, national variations exist between screening services. The main difference between organisations that was revealed in the interviews was who followed up with patients during the surveillance period. Screening services are commonly organised and structured to meet and examine many patients over a short period of time.

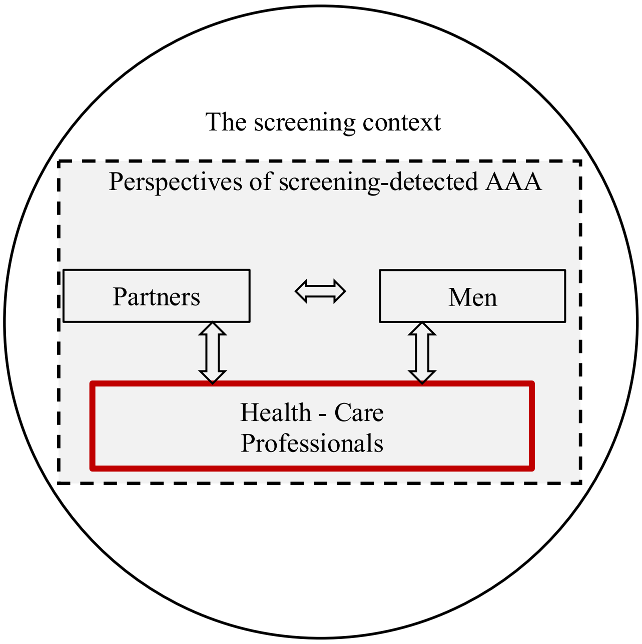

Figure 9 Illustration of the case perspectives of screening-detected AAA, with a focus on health care professionals' perspectives on caring for participants who have a screening-detected AAA (highlighted in red).

4.5.1 Experiencing the unexpected

For health care professionals, experiencing the unexpected meant that they diagnosed men with an AAA at the screening and had to experience their reactions and address their concerns.

According to their perceptions, the men were unprepared when coming to their first screening examination. Too much different information was included in the invitation to the screening examination was mentioned as a possible reason for this. However, others thought that there might be too little information in the invitation. Among the professionals, it was challenging to reach a balance regarding the information provided in the invitation. They wanted to reach out with the message that AAAs are asymptomatic and could rupture if left untreated, while also downplaying the situation and informing their target audience that they can control

AAA progression through screening and treatment with an elective surgery when it was time.

The health care professionals described that the first screening examination was often done under stress. Meeting the men for the first time could be a challenge since they did not know how they would react to an AAA diagnosis. As stated by one of the professionals in the interviews:

I think it is difficult because the men react so completely differently. Some become really afraid and some just shake their shoulder as if nothing had happened (Interview IV).

Furthermore, they found that it was a lot of information about the diagnosis, disease progression and surveillance to provide in a short time. Some also noted that it was difficult to reach out with the information they wanted and needed because the men were often under stress and pressure. The health care professionals perceived that the men were uncomfortable and wanted to leave the examination room as soon as possible. This was observed in the dialogue between two participants in one of the interviews.

In my experience, the men are really not receptive to information at the first screening examination…just that they got the message about the diagnosis and that they belong to the percentage that actually suffers from it makes it difficult to reach out with the information.… I agree and seldom tell them much during the first *screening since they look like question marks and just want to leave through the door and disappear (Interview I).*

Moreover, the interviews highlighted that professionals perceived that the men found it hard to change from being at the screening for health control to getting a diagnosis. It was more comfortable for the professionals to reach those who had questions, but they were afraid that the men also left and started to reflect after leaving the screening centre. Therefore, they considered having closer contact with the men soon after providing an AAA diagnosis, which was already implemented at one of the screening centres and mentioned as positive. However, the professionals noted that they were available if the men had any further questions or concerns when they returned home and told them that they were welcome to call them.

The health care professionals described that they also found it difficult to care for the partners of the men. Since they seldom met them at screenings, it was hard to reach out to them to determine how they felt or whether they had any concerns. The professionals thought that the partners still might be working, thus making it difficult for them to accompany the men. The only time they met the partners was when men had disabilities or language-related difficulties. However, the health care professionals were aware that knowledge of an AAA diagnosis might be burdensome for the partners. At the screening, men explicitly asked for the diameter measurement of their AAA and continued to explain that it was important for their partner to know. Some professionals expressly told the men, “When you come back home, you can tell your partner about this.” They mentioned that it might be more comfortable for the men to think about the information that they received. Some clinics had attempted to partly solve this problem by reaching out to partners with written information provided through the men, which other clinics are currently considering. This was mentioned by one health care professional.

It is so difficult with the partners. But I think if we have some written information, then the partner would be more involved in the diagnosis. Now we do not reach them at all because they seldom accompany the men. And even if they come, they just waiting in the waiting room (Interview IV).

Furthermore, others had considered more actively inviting partners to consultations or subsequent screening examinations. However, the interviews highlighted that while the partners were more than welcome to join, this was the men's choice and responsibility.

4.5.2 Being reminded of fragility

The health care professionals were fully aware that knowledge of an AAA diagnosis affected the participants' lives to different degrees. However, for the health care professionals, being reminded of fragility meant meeting the needs of participants and reducing the fragility that they experienced in their lives due to the AAA diagnosis. According to the professionals, it was their responsibility to address the participants' worries and concerns. However, they mentioned that while worrying about health was expected and normal, it was their responsibility to be as precise, honest and open as possible so that the men and partners can find balance and think more rationally about their fragility.

Most of the care for men diagnosed with an AAA and their partners is meant to inform, update and remind participants about the importance of the given information with the primary focus of keeping them calm throughout the surveillance period. Besides providing the relevant information, they found it difficult to provide any other support apart from being available to them.

I do remember one man clearly, he was so nervous. He was under surveillance for many years and he was always nervous every time he came here. But finally, he went through an operation of the AAA. I asked him if he regretted that he first attended the screening due to his concerns and worries, but he did not. But it is really difficult to know how we could have supported him in any other way. But at least he had the telephone number and could call us (Interview III).

Additionally, the participants seldom expressed their concerns and thoughts to the professionals directly. Instead, they asked indirect and other questions; however, the health care professionals understood that they had other worries. For example, participants would call the professionals to ask about the time of their next examination just to be certain that the health care service did not lose them in the system.

The health care professionals found themselves comfortable with the situation of caring for participants and had experience in caring for vascular patients. Their working experiences were highlighted to strengthen their trustworthiness among the men and their partners, which made the participants trust the professionals as well as the screening service. To further improve the relationship between the participants and the professionals, a desire for greater continuity during the surveillance was expressed among the professionals in the groups. Besides giving them the opportunity to follow up on the participants' concerns, greater continuity would also provide them with a chance to further understand the participants' situations and the challenges they experience when living with the knowledge of having an AAA.

The professionals also received questions regarding travel and concerns about insurance if something should happen with the AAA while they were abroad. In general, they responded that they should continue to do what they like to do. However, some professionals were unsure how to respond to this question, especially when the AAA expanded and came closer to requiring an operation. However, it was also mentioned that the professionals had close contact with the screening team and could always consult and ask each other when they were unsure about something.

Furthermore, it was highlighted that the professionals often heard questions about the operation. The reason for waiting for an operation was unclear for some participants, even though the professionals had tried to explain. However, the professionals also heard relevant arguments from the participants for not waiting for an operation. One example of such an argument was that their general health might degrade if they had to wait for surgery due to increasing age. The health care professionals expressed that the questions and concerns of participants changed in nature when the AAA increased in diameter and came closer to an elective surgery being offered. The health care professionals also gave more detailed information about the operation and the preparations for it. The risks and negative consequences related to the operation were then outlined by the medical physicians, either at the screening or at the vascular clinics.

Apart from concerns and questions about general impacts on patients' lives, one significant concern that professionals addressed was AAA ruptures. The professionals mentioned that this concern might be related to the previous experiences of families and friends with AAA ruptures. However, the professionals were critical towards themselves regarding this concern and mentioned that if someone back home was worried about a rupture, they had failed to inform them. The professionals confirmed that if they met anyone with a heavy psychological burden related to the AAA, the screening system was flexible and they always had the opportunity to let the person come for extra screening or any other contact. It was also noted that a very small number of men had undergone surgical treatment before reaching a diameter of 55 mm due to psychological impacts.

4.5.3 Balancing a changing relationship

For the health care professionals, balancing a changing relationship involved providing recommendations for concerns about balanced relationships between diagnosed men and their partners. However, such recommendations were mainly focused on information and support regarding the participants' lifestyles.

Based on the health care professionals' work experiences with AAA screening, as well as their knowledge from previous research within the AAA screening context, they knew that several concerns affected the lives of the participants. One of these was related to physical activity and whether they could continue to be physically active. The professionals attempted to explain that patients could continue to live as they did before they knew about the AAA.

The AAA is nothing that you should take into account in your daily life. Try to continue as before (Interview V).

Furthermore, health care professionals tried to support men regarding their smoking habits. They pointed out the importance of smoking cessation and having control over their blood pressure. However, the routine for this process differed among the screening centres. Some of them prescribed medication for high blood pressure, while others did not. Moreover, the routines for smoking cessation also differed between the clinics. While one of the centres had the opportunity to consult with a lung clinic to help those that still smoked, they seldom did so. However, health care professionals always followed up on smoking habits during subsequent follow-ups. Despite this, they did not have any opportunity to further support the men. The professionals stated that it was challenging to motivate the men to quit their smoking habits. Ultimately, they knew that they could only inform them and that it was each man's responsibility to control their smoking habits.

It can be tough for some (to quit smoking). We do not have the routine to just send a referral and someone else takes care of it. It is often such an old habit (to smoke). I find it so difficult to actually motivate them to quit smoking (Interview IV).

4.5.4 Summary of the health care professionals' perspectives

This sub-section of the results presented the health care professionals' perspectives on screening-detected AAAs, with a focus on their views regarding the screening and how they perceived the participants' emotions and reactions. This information was presented under the three categories: 1) *Experiencing the unexpected*; 2) *Being reminded of fragility*; 3) *Balancing a changing relationship.* For the health care professionals, it was important to balance the information, provide the important parts and not scare the men. This balance was of importance to both treatment and lifestyle impacts from the invitation stage and throughout the entire screening surveillance. Apart from providing relevant information, it was their responsibility to support and minimise the men's emotional challenges and concerns during the screening surveillance process. The results also indicate that the health care professionals seldom met the partners at screening. Furthermore, suggestions for the screening service were provided.

4.6 Cross-unit analysis: The screening surveillance journey

4.6.1 Introduction to the analysis of cross-embedded units

This subsection of the result chapter will present the cross-analysis of the embedded units, *The partners*, *The men*, and *The health care professionals* of the case *“Perspectives of screening-detected AAA”* (Figure 10). The cross-analysis of the embedded units will be illustrated as a screening surveillance journey and presented under two subcategories; *Navigating through a new life situation* and *Anchoring to a life with an AAA.* First, under each subcategory, an interpretation focusing on the contrasts between the embedded units will be highlighted. This will be followed by narrative stories highlighting the participants’ experiences. Lastly, the health care professionals’ perceptions and experiences of taking care of men with an AAA and their partners, as well as their views on the support and care given within the screening context, will be described.

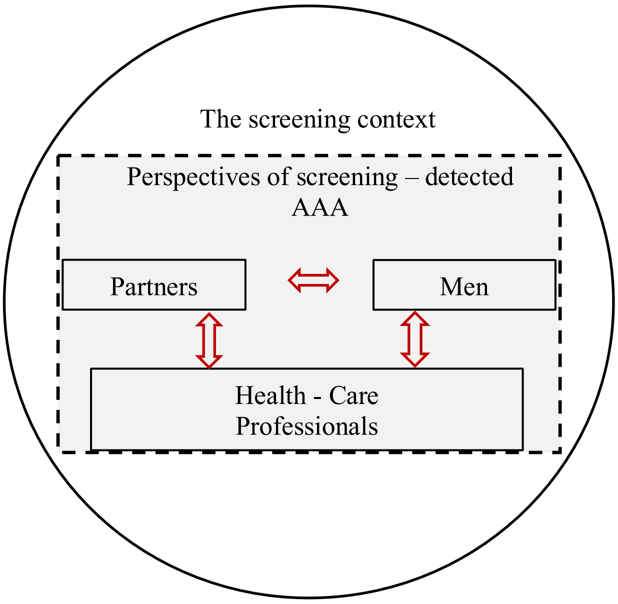

Figure 10 Illustration of the case with the three embedded units. This focus of this subsection is the cross-embedded unit analysis with descriptions of the differences between the units, as marked by the red arrows.

4.6.2 Navigating through a new life situation

Navigating through a new life situation illustrates the contrasts in how the men and their partners react as well as their emotions and how they learn about AAAs. The participants attempt to adapt to the new life situation of living with an awareness of a screening-detected AAA.

The screening surveillance journey began when the men were invited by post for a U/S of their aortas. The invitation was received with gratitude, even if an AAA was something unknown to the participants. Nevertheless, since it was addressed by the health care service, they took screening attendance seriously, almost as a duty. The men marked their examination dates in their calendars hoped they did not belong to the relatively small group of individuals suffering from an AAA; however, they did not reflect much upon it. For their partners, the time between the invitation and screening involved mentally preparing themselves for a potentially serious condition.

The following is a description from men receiving the AAA screening invitation:

I received the invitation just after my 65th birthday and my wife and I were really grateful that screening for AAA is part of the health care system. This is something that all men should take seriously. We have discussed it with friends and stated that they should not hesitate to go. We—neither me nor my wife—reasoned that it was better not to know. I do not really know anything about AAA and neither does my partner, at least not more than I read in the leaflet that came with the invitation. Some of the information was a bit frightening and I hoped that I was not one of those that have an AAA, but you never know. I do feel a bit sorry for my wife because she seems to think more about it. But it was so clear for both of us that I should go.

From the health care professionals' perspectives, the balance between information on the seriousness of the condition and the options for AAA treatment was something that had been discussed over the years within the profession. As they were well aware, receiving news of a screening-detected AAA will change people's lives. This has led to the information provided in the invitation being similar across the entire country.

Regardless of mental preparations, none of the participants mentioned that the message about the diagnosis was something positive and the participants needed to navigate through their initial reactions. However, the methods of expressing emotions and reactions regarding the diagnosis differed between the men and their partners. The men wanted to hear that the screening was unnecessary and there was no further need for follow-ups. They said that they were surprised, baffled and unhappy. The partners who did not attend the examination had to listen to their diagnosed partner's interpretation after the screening. Notably, the partners expressed deep disappointment, shock, sadness and thought it was unfair. Partners reaction when their men came back home after the first screening examination was as follows:

When he came back home after the screening, he was a bit shaky and I noticed that something was wrong. Then he told me about the information from the providers. I tried to listen carefully, but for me, it seemed that he did not have enough information himself or he had missed some of the information. However, after our discussion, he seemed relaxed and calm. I thought everything was so unfair and I became very sad. It was like a new situation arose. Why should this happen to him and us?

The overall impression from the health care professionals was that while the men received the message about their diagnosis with ease, they could understand that it brought new thoughts when they left the clinic. It was a lot of information, mostly general information about an AAA, given over a short time. Once again, balance was important (i.e., how much and what type of information the men were susceptible to). Additionally, they confirmed that they seldom met the partners at the screening. Thus, it was unknown whether they received the message about the diagnosis.

The participants continued to navigate through different sources of information. This information largely originated from the internet or leaflets from the screening clinic. Furthermore, some information was gained from the previous experiences of relatives, friends or work in an attempt to learn about their diagnosis, what an AAA is and how it could affect their lives.

The information from health care professionals was perceived with huge variation in satisfaction. The men were satisfied when they received information about the size of their AAA, the date for the next follow-up and that they could continue to live as they did before their diagnosis. They mentioned that they did not obtain more information because they still had not reached the line where AAAs can become dangerous. However, during the screening surveillance, they expected more information. Among partners, this information was stated as incomplete and superficial. The partners doubted that the men had sufficient knowledge about AAAs, which made them feel uncomfortable and worried. Furthermore, it led to more questions and a certain level of uncertainty. The partners highlighted that it was important to determine the reasons for getting an AAA and what they could do to prevent it from growing or slow its progression. However, partners noted that men finding information on the internet only led to more confusion. Some men found information on the internet if they were lacking some information, especially at the beginning of the process (i.e., after the first screening). However, the difference between the men and the partners was that the men had the opportunity to meet the professionals face to face and often noted the calm and trustful manner in which they were informed about their AAA.

The story following illustrates the contrasts that occurred according to differences in the way partners received the information.

When he came back home, he told me that the AAA was 50 mm and that he should have the next screening examination in 6 months. But I immediately started to think of one of my costumers, who told me that his aneurysm ruptured. Although this costumer was a smoker and a bit overweight, my husband and I live a healthy life, so I wonder why he should suffer from this. My husband told me that they could operate on him later. But I am so worried and cannot understand why they are waiting when they know about it. My husband only says that they will inform him later when it is time for him to go through the operation and he seems to be pleased with that.

According to the health care professionals, information about the possible reasons for getting an AAA were given both orally and in writing. Notably, they tried to include it in the information about smoking. However, the professionals also stated that it would be a relief for them to mention that it could be a genetic condition since it would make it seem less shameful. However, even if they tried to be clear about the possible causes for developing an AAA, these could be perceived as muddled for the participants. Furthermore, health care professionals noted that the most frequently asked question was about the reasons for delaying an operation and mentioned that they explicitly tried to explain this to the men.

4.6.3 Anchoring to life with an AAA

The subcategory *Anchoring to life with an AAA* focuses on the contrasts of adapting to and coping with the new situation of living with an AAA diagnosis. This could range from immediate acceptance to struggle. Moreover, it could involve changing one’s lifestyle to adapt to daily life situations. Depending on the growth of the aneurysm, time spent in the screening programme and other life events, this level of adaptation could be affected and changed.

The impact of lifestyle on AAA progression was unclear for both men and their partners. It was also unclear whether any changes actually prevented AAA progression. However, there were inconsistencies between the groups. The men mentioned that they were asked about their smoking habits at the screening. The men also mentioned that while they were responsible for their health, they did not want to change their lifestyle if it affected their QOL. For example, this could involve continuing to smoke, eat good food and/or drink wine. They referred to the health care professionals' words: "continue to live as normal".

Conversely, their partners had intense ambitions and considered it important to do what they could to prevent AAA progression. They believed that living a healthy life could not be detrimental at the very least. Therefore, they attempted to support and encourage the men to change their lifestyles. For example, this could involve preparing what they considered to be healthy food for dinner, which often included vegetables. Partners also mentioned that they encouraged the men to be more physically active. Sometimes they joined the men at the gym or went out for walks together. Notably, encouraging and supporting smoking cessation became sensitive and frustrating for the partners; therefore, they often abandoned such efforts. The partners' benevolence could lead to negative emotions for the men since the men already knew what they needed to do. Thus, they could become highly sensitive when their partners attempted to provide constant encouragement.

The following narrative illustrate partners descriptions of how they try to support and encourage their men having a healthy lifestyle:

We eat traditional Swedish food and I always try to serve vegetables. But he is not that fond of vegetables or fruit, so it is not easy for me. I take walks every day with our dog but he has such pain from his knees now that it is hard for him to come along. I always think that if I continue going out for my walks it might inspire him as well. When it comes to his smoking, I have always disliked it and now I have given up. It seems so difficult for him to give it up and it is almost like it would be worse for him to refrain from it. He knows that I don't like it. For me, it is like he does not care about our common future. However, they asked him about smoking when he was at the screening, but they also said that he should continue to live as normal. He means that if they (health care professionals) really meant that he should quit and that it was so important, they should have told him to quit.

According to health care professionals, it was standard to ask about men's smoking habits and encourage them to quit if they were smokers. This was also something that they tried to follow up on at subsequent U/S examinations. They mentioned trying to explain that smoking could be a potential reason for getting an AAA. However, they did not have any resources for smoking cessation other than informing them about the risks. Except for smoking, they did not provide any other information regarding lifestyle changes that could improve their outcome.

Notably, AAA diagnosis impacted the participants' daily lives in various ways. The men often returned to feeling normal, without any notable physical changes in their bodies that could be related to AAAs. They made comparisons to other diseases and defects such as knee injuries, toothaches or other painful conditions that were mentioned as harder to stand and made a greater impact on their lives when compared to the “silent” effects of AAA. Furthermore, another explanation for AAA not affecting men’s lives is related to their personality. Some men were simply not the type of people that were bothered, while a rupture could even be a good way of ending their lives. Conversely, for the partners, a rupture represented a constant threat. Even if they trusted health care professionals, they continuously observed their diagnosed partner’s health status. The correlation between AAAs and ruptures was evident, which caused stress for the partners. Therefore, the partners prepared for the worst. Some created detailed plans of whom they would call and how they would try to save their men’s life if their AAA ruptured. It was also evident that they were worried that something could happen with the AAA when they did not know where their partner was, thus being unable to save his life. To maintain control of the situation and AAA progression, it was desirable to have more frequent follow-ups. Furthermore, even if they knew an operation could be dangerous, they considered it to be the only solution that could remove the AAA. This was expressed as part of their desire to return to the life they had before the AAA was detected. However, the partners also mentioned that they needed to prepare themselves for a potentially dangerous operation with a fatal outcome. In contrast, the men noted that they wanted the operation and did not consider the risks in great detail. The following stories exemplify the partners’ daily impact in comparison to the men’s experiences. This story also illustrates thoughts that arose as they approached the AAA operation. The following descriptions from men highlight how the AAA impacted their daily lives.

I am living with thoughts about the AAA day and night. Like today, he went for his weekly bowling. Then, I immediately start to think, "I hope no one calls me to tell me that he is not feeling good". Or like yesterday when we were out in the garden and I asked him not to chop the firewood, he insisted there was no danger in doing that. I noticed that he gets irritated when I take over the duties that he used to do. He wants to be independent. During the night, I listen to check that he is still breathing.

Every spring and summer, I spend a lot of time in our garden. And before this diagnosis, it was me that did everything out there. But now, my wife is more or less running after me, telling me what I am allowed to do or not. That irritates me so much. She even asks our neighbour for help. I do not want it to be like that. So instead, I have constructed a machine that helps me to cut the hedges and I also bought a robotic lawnmower. I mean, they told me I could live as normal—except for carrying heavy things—and I do not want my wife to do everything, even if I know she cares for me and does not want anything to happen with the AAA.

Minimising the impact of AAAs on the participants' lives was an important goal for health care professionals. Therefore, lifestyle and other restrictions were seldom given, except for avoiding heavy lifting. They also emphasised that the participants should continue to live as normal, which could be seen as a strategy to minimise the QOL impact. Since extreme abdominal pain can be a sign of a rupture, they mentioned that the participants should contact the health care service if that occurs. Based on what they heard, their perception was that the AAA diagnosis had a minimal impact on the lives of the participants.

4.7 Chapter summary

In this chapter, the analysis of qualitative data on the perspectives of a screening-detected AAA with the three embedded units was presented. It addressed variations within each unit as well as differences between the groups. The first three subsections were divided based on three categories: “Experiencing the unexpected”, “Being reminded of fragility” and “Balancing a changing relationship”. The analysis was followed by verbatim quotes from participants in the interviews. The fourth subsection highlighted the contrasts in their experiences, was presented as a process and illustrated as a screening surveillance journey based on the following two categories: “Navigating through a new life situation” and “Anchor to a life with an AAA”. The next chapter discusses how these findings align with the relevant literature.

CHAPTER FIVE

DISCUSSION

5.1 Introduction to the discussion chapter

This chapter will further interpret and discuss the findings presented in the previous chapter. The experiences related to living with a screening-detected AAA were described both from partners' and the men's (mentioned as participants) perspectives and the contrasts in their experiences were illustrated. Furthermore, health care professionals' perceptions and experiences of caring for men with an AAA and their partners have been presented. The findings highlighted recurrent experiences of living with the awareness of an AAA and being under surveillance. Moreover, they outlined the process of participants adjusting to a new life situation of living with an AAA diagnosis. Presented as a screening surveillance journey, this process was developed through within analyses of the men's and partners' experiences, respectively, health care professionals' descriptions of caring for the participants as well as a cross-analysis. The discussion chapter continues this journey by highlighting the differences from the analyses and further interpreting and discussing possible contributors and assumptions that may have an impact on how their perceived experiences align with relevant theories, concepts and the literature. Furthermore, the limitations of the QCS method and strategies for adapting rigour are also discussed in the present chapter.

5.2 Discussion of the results with existing evidence

5.2.1 Initial experiences of the screening-detected AAA

In Sweden, all 65-year-old men are invited for a screening of their aorta. The findings of the present study revealed that the participants took this invitation as an obligation. They mentioned they did not even reflect on the invitation. Instead, they just marked the appointment without considering an optimal outcome option. This could explain why compliance with the Swedish national AAA screening is relatively high. Compared to other screening services in Sweden, the compliance for participating in AAA screening has been reported as 84% (Wanhainen et al., 2016), while breast cancer screening has a reporting compliance of 75–85 % (Olsson et al., 2000) cervical cancer has 55% compliance (Rodvall et al., 2005) and colorectal cancer has 39% compliance (Blom et al., 2008). However, due to the high compliance (Wanhainen et al., 2016) for AAA screening and the findings of this study regarding men's perception of the invitation, this health care service seems to reach the participants in an adequate and balanced way.

That screening of the aorta for eventual AAAs is a voluntary offer needs to be highlighted, especially since a literature review revealed that people attending prostate cancer screening or AAA screening often perceived the diagnosis as unexpected, which resulted in psychological harm (Cotter et al., 2017). When participants decide to participate in screening, health care professionals need to inform patients of potential psychological impacts on their lives at an early stage in the process. The health care professionals involved in the AAA screening participated in a national initiative to improve the provision of information to men. For example, it has been mentioned that the balance of information is important. It is also important to convey the message that an AAA might be dangerous if not detected in time and that elective treatment is possible and safer than an emergency operation. However, voluntary participation might also need to be underlined. Furthermore, professionals have developed these invitations so that the same information reaches all 65-year-old men nationwide. Thus, the project of developing this information is essential. Unfortunately, the collaboration with patients observed in the literature (Armstrong et al., 2018; Graham, 2011) regarding the development of information has been largely overlooked. Notably, such collaboration can increase the compliance to and validity of the information presented. To involve patients and collaborate with them during the development phase might also be essential in reaching out to districts with lower compliance with the AAA screening. Low compliance has previously been noticed in areas with a lower socioeconomic status associated with low income, a higher number of immigrants and a higher unemployment rate (Zarrouk et al., 2013). However, the development of such invitations and their information is nevertheless necessary. This would present men with the opportunity to make a voluntary choice to participate in AAA screening, regardless of whether they are affected by a gap in understanding around concepts and words used in AAA screening contexts in the communication between physicians and patients (Strijbos et al. (2018) or inadequate health literacy.

The men and the partners received messages about AAA diagnosis in different ways, which might explain their different reactions. The men received the message about their aneurysms at the first screening examination by the professionals that conducted the U/S examination. The men then returned home and felt satisfied with the information received, which they repeated to their partners (i.e., AAA size, that they could continue to live as before, and that they will be under the health care professionals' control). In contrast, the partners mentioned that this was superficial and that they only had access to secondary information. The partners assumed that the men did not have more knowledge about AAAs when returning home with a new AAA diagnosis. Although this can partly be true, the literature suggests that a person diagnosed with a life-threatening disease faces several challenges and must balance between risks and benefits before deciding to disclose disease-related information with others. Notably, emotional impacts may be an underlying feature in that decision (Checton & Greene, 2012). As emphasised by Greene (2015), there are mainly three aspects that a person considers before deciding to share information with others. The first aspect involves assessing information regarding the diagnosis. Greene (2015) argued that people consider information related to components of stigma towards the disease, the prognosis, relevance for others, preparation and symptoms. In comparison, components that might have impacted the men in the present study and their decision to disclose include their prognosis, symptoms, preparations and the relevance for others. After the initial screening, the men mentioned that their AAA diagnosis was an unexpected message and that they were surprised. However, even if their partners mentally prepared themselves, they still mentioned stronger emotional reactions such as shock and sadness. Furthermore, the prognosis of the disease was unclear for the men after their initial screening examinations. They highlighted that they thought further information would be provided over the screening surveillance process, specifically when the AAA expanded towards a diameter of 55 mm.

Additionally, a study conducted by Ericsson et al. (2017) that evaluated satisfaction with the information provided by health care professionals to men with an AAA diagnosis showed significantly higher satisfaction with the information provided at baseline when compared to a follow-up after 6 months. In the same study, it was also shown that the men attempted to learn more about their diagnosis after the screening when compared to the follow-up. Although it can be assumed that men are satisfied with the information received immediately after their initial screening, more concerns are raised during the screening surveillance process. This indicates that continuous support and updated information from health care professionals are needed to reduce the psychological impact of an AAA prognosis. Since most AAAs are asymptomatic (Wanhainen et al., 2019), the men could not get a sense of any physical differences or changes in their bodies, which can be assumed to reduce their sense of disease severity. Instead, the absence of symptoms led to the men to trust in and rely on health care professionals, which can reduce uncertainty regarding the diagnosis (Mishel, 1988). However, this was not observed for the partners since they seldom accompanied them for screenings.

Greene (2015) noted that a person with a disease diagnosis also needs to assess the person who receives the information before deciding on whether and what to share. Generally, people disclose such information to those they are close to. Notably, relationship quality was also mentioned as an essential component that increases the willingness to disclose. However, among men with prostate cancer, 3 out of 10 men in a relationship experienced difficulty in sharing sensitive topics and confiding in their partners (Helgason et al., 2001). Furthermore, the anticipated response was mentioned as necessary when sharing personal and sensitive information. The expected reaction can either be communicated in words or as an action. Goldsmith (2015) showed that people can have more open discussions regarding certain aspects of a disease (e.g., physical changes) but avoid or find it difficult to elaborate on more sensitive aspects (e.g., death or fear for a common future). This is in line with the experiences described by the men in this study, who did not want to discuss negative topics such as disease and death with their partners, while others mentioned that they waited until the AAA became more critical. Furthermore, if the men believed that their partners would react with strong emotions, they might instead try to protect them by keeping the information to themselves. However, it initially seemed stressful for the partners in this study to obtain only superficial information. Although shown in a study by Nilsson et al. (2020) using a newly developed e-health tool for AAA patients, patients found the device's information to be of value for their next of kin. Furthermore, the same study noted that patients appreciated sharing information with people they were close to (Nilsson et al., 2020). Traditionally, from the perspective of health care professionals, keeping information about an illness to oneself has negative consequences (Bradshaw, 1995). According to the professionals in the current study, men ultimately decided what type of information they wanted to share. However, they welcomed their partners to join to the examinations. It has been indicated that a lack of immediate and direct communication between health care professionals and partners can be seen as a sign of exclusion, which can cause further misunderstandings within a relationship (Maughan et al., 2002). To give partners an opportunity to receive direct information, develop a sense of trust towards the screening system and provide the partners with emotional support, it is likely beneficial for the men and partners alike to attend the first screening together. Furthermore, partners can support men that receive an extensive amount of information within a short time during the initial screening since they might not be receptive to a wealth of information. Another explanation is seen in the study by Nilsson et al. (2017) noted that patients with AAAs felt blocked by their fear and struggled to listen to the information provided by professionals.

5.2.2 Appraisal of the AAA diagnosis

Living with a screening-detected AAA diagnosis results in a life with ambiguous experiences. Such double-edged experiences can range from being pleased to know about the diagnosis and that health care professionals are keeping it under control to feeling imminent worries about a worsening AAA that may rupture. This range of experiences relates to a variety of uncertainty towards the adjustment of a new life situation with AAAs. While uncertainty is natural in human experiences, it becomes more prominent when an individual is exposed to a threat, which an illness can certainly be interpreted as (Mast, 1995; Mishel, 1999). According to the uncertainty in illness theory (Mishel, 1988), uncertainty can be viewed as an opportunity or a danger. This theory suggests that uncertainty depends on the individual's capacity to form a cognitive framework known as "cognitive capacity" (Mishel, 1988). Furthermore, the individual's interpretation of uncertainty also depends on their social network, contact with health care professionals and whether they can relate to similar situations, which Mishel (1988) called "Stimuli Frame" and "Structure Providers". Moreover, this appraisal is related to the individual's capacity to construct beliefs, which were mentioned as "Illusions" (Mishel, 1988, 1990). In the present study, the participants often considered previous experiences with ruptured aneurysms via family members, friends, or working experiences. These can be assumed to affect the outcome of an appraisal to a negative experience for screening-detected AAA due to its interpretation as a danger for the participants. This indicates that health care professionals must give sufficient information and evaluate patients' understanding of the information provided.

In the present study, the risk of AAA rupture was appraised as a concern and danger. Furthermore, the participants felt insecure about the procedure of waiting—waiting for the next U/S examination, waiting for surgical treatment and—even worse—waiting for a rupture. Furthermore, the ambivalent feelings and thoughts towards surgery stated in the results of this study can be appraised as a danger for the participants. Danger may impact the patients' response to their illness and affect the psychosocial outcomes and adaptation of the disease (Neville, 2003). Appraising uncertainty as a danger is also predicted to impact a person's QOL (Bailey et al., 2007). Additionally, danger is also related to emotional reactions such as fear, worries and stress (Brashers & Hogan, 2013). However, as noted in the literature review chapter, studies that evaluated anxiety among men with AAAs using the HADS instrument did not observe any significant differences over time in their results. One possible explanation for this might be in line with "credible authority" (Mishel, 1988), which is related to trust in the health care system and its professionals. In the present study, the participants mentioned feeling safe under the control of health care professionals. In contrast, the expectations they had for treatment led to questions and worries. Consistent with the "event congruent" introduced by Mishel (1988), if patients have unmet expectations regarding the treatment or if the treatment does not alter the illness process, then uncertainty increases. It is likely that participants in the present study experienced uncertainty and felt anxious when waiting for confirmation of their AAA status. Furthermore, when they experienced a hospital visit “just” to do the U/S examination, it involved a new period of uncertain waiting. This indicates that the HADS instrument may not be sensitive enough to detect the type of anxiety expressed by the participants. However, according to Mishel (1988), a stable “credible authority” that refers to trusting professionals and the care system can promote the “event congruent.” This highlights the importance of accessible care for participants—whenever their concerns appear—using either an available contact nurse or alternative e-platforms where concerns can be raised from the participants.

The lack of physical discomfort or notable changes in the body, is as well as in the initial stage of the screening surveillance process, a component that affected the appraisal of the situation among participants. Notably, this could lead to a feeling of not having control over their own body. This is in line with a study evaluating uncertainty among men with prostate cancer under active surveillance care. The knowledge of having cancer growing in their bodies without feeling any difference (or only occasional symptoms) resulted in increased uncertainty (Bailey et al., 2007). Thus, the men with prostate cancer incorrectly related other physical changes with disease progression. This was also stated by participants in the current study when they related all forms of abdominal pain to AAAs. Furthermore, the pain was related to a strong fear since they thought that their AAA had ruptured. On the other hand, a lack of symptoms was also seen as something positive by the men in the current study. They made comparisons to more painful conditions and mentioned that the AAA was not difficult to tolerate. While asymptomatic AAAs may decrease the physical impact for participants, they could intensify uncertainty regarding AAA status. The lack of symptoms was also something that emotionally affected the partners in their daily lives. Notably, emotional effects (e.g., via stress or anxiety) have previously been identified in the partners of patients with prostate or gynaecological cancer (D'Ardenne, 2004; Maughan et al., 2002). However, the partners in these studies were often reminded of the disease through physical changes during disease progression. While disease progression was not noticeable for the partners in this study, the knowledge itself still affected them. Living with an uncertain outcome was stressful and an ambivalent desire to have surgical treatment for AAA was expressed. This was seen as the only solution to get rid of the AAA and its negative impacts and continue with a normal life. The desire for surgical treatment or active treatment was also described among men diagnosed with prostate cancer. Even if the side effects or complications were known for these men, it was important for them to undergo an operation to get rid of the diseased part and continue with their lives (Xu et al., 2012). As noted in the literature review chapter, patients that undergo surgical treatment of their AAA improved their QOL shortly after the operation, which might be related to the desire to return to a normal life (Ashton et al., 2002; Lindholt et al., 2000). However, undergoing surgical treatment was not only viewed positively among participants in the current study. For example, some men associated surgical treatment with decreased health status, while their partners were afraid that they may not survive the operation. A study that compared psychological impacts between prostate cancer patients under surveillance with their partners' outcomes found that the partners had significantly higher levels of reported worry regarding the surgical treatment when compared to the men themselves (Cliff & MacDonagh, 2000). It has also been shown that partners to prostate patients had a significantly higher level of worry regarding treatment side effects (Oba et al., 2014). However, the partners' reactions in this study were not related to mistrusting the surgeons. Instead, they were related to their previous experiences since they had heard that many did not survive AAA operations. Similarly, previous studies have shown that when women with cancer heard about others having cancer or listened to relevant information in the media or from other sources, it triggered uncertainty about their illness (Gil et al., 2004). Even if this experience was from the patients' perspective, it can be assumed that partners can experience it similarly. Nevertheless, it might not be surprising that surgical treatment increases anxiety and emotional impacts since it is a stressful event for both the men and the partners. This was also noted among men and their spouses when one spouse underwent coronary bypass or another coronary intervention (Roohafza et al., 2015). Notably, this indicates the need for further support from health care professionals when approaching the operational treatment of an AAA. The fear of both a rupture and an operation with a fatal outcome might explain why the most common question asked among participants is why they needed to wait for an operation. Again, this proves the need for clear and easily accessible information for participants. Mishel (1988) emphasised that trust towards health care professionals can reduce uncertainty if they can clarify events for the patients. The health care professionals were fully aware that the participants found it strange to wait; however, they also found it difficult to fully explain the reasons for this delay in an understandable manner. Notably, they were aware of that such misunderstandings could lead to suspicions towards the screening care. This indicates the need to further develop information and psychosocial support for the men and their partners. For example, an available contact nurse who can meet emotional concerns when they occur and provide advice might be of help for the participants.

The way how the participants interact with information is an important component of how they appraise and continue to value uncertainty. This can either reduce, increase or maintain the experience of uncertainty (Brashers, 2001). If the situation is viewed as dangerous, a motivating factor could involve seeking information to mitigate the threat or confirm/disconfirm one's own beliefs about an illness. Other studies have found that individuals who appraised uncertainty as negative were predicted to search for more information (Brashers, 2001; Brashers & Hogan, 2013). Information on the internet can be a resource that provides access to formal information as an adjunct to information from professionals (Bessell et al., 2002; Wright, 2000). As noted in the findings of the present study, the participants wanted to know more about their diagnoses and used the internet to find further information. Despite the availability of supporting information on the web, some men found the information confusing, while the partners found it frustrating when their diagnosed partner searched for information online. For the partners, it led to further worries since they were afraid that the men would read incorrect information. Moreover, patient-related information on the internet regarding AAAs has previously been considered insufficient (Goldberg et al., 2010). Although the information available online has likely been updated and improved since the aforementioned study was conducted, health care professionals can view this information-seeking behaviour as a lesson—especially since another study of patients with AAAs showed that professionals could not address their patients' learning needs (Nilsson et al., 2017). Additionally, it has previously been observed that the relationship between uncertainty management and information-seeking increases exposure to different types of information (Rains & Tukachinsky, 2015). Apart from this frustration and confusing perception, a systematic review (Ravitch, 2016) also noted that patients who searched for information online experienced adverse impacts on their relationships with health care professionals. This is because patients developed increased knowledge about their condition and could thus question the traditional information provided by their health care professionals. Furthermore, different screening centra are differently organised and have different routines regarding the content and information provided. Therefore, to address inequity in health care and individual needs for sufficient information, health care professionals might need to consider supplementary information platforms and the further development and evaluation of e-health tools for the AAA screening population.

Notably, Barbour et al. (2012) noted that another way of managing uncertainty involves avoiding health information since more information can raise new concerns. Discussions of how to distinguish between avoiding health information or being passive in seeking information are currently ongoing. Passive searching for information has been classified as a lack of interest for information (Case et al., 2005). However, avoiding information is done for a reason. Barbour et al. (2012) noted that such reasons can include patients wanting to maintain hope, resist overexposure, manage flawed information, accept the limits of their actions and continue with their lives. Possible explanations for this behaviour among the men in the current study could be that they knew there was nothing they could do to stop AAA progression. Thus, they actively choose not to learn more about their diagnosis. Notably, this study could not discern any information-seeking behaviour apart from partners feeling that they only had access to secondary information and the participants—especially the men—searching for information online. However, it can be assumed that the behaviour was related to either being satisfied with the information provided or avoiding information as a coping strategy. This can be a challenge for the health care professionals due to the limited amount of time available during consultations to get a sense of individuals' needs and desires for information. However, the active role of professionals needs to be encouraged so that the men do not get the feeling of being left alone with their concerns.

The uncertainty of living with an illness can also be appraised as an opportunity since individuals generally aim to maintain or decrease the uncertainty. Thus, the outcome could be more optimistic and give hope (Brashers et al., 2000), which can be considered an easier process for participants in this study when adjusting to life with an AAA diagnosis. Under special circumstances (e.g., when people prefer not to know), uncertainty can be preferred or desired to extend a positive mood or serve as a source of inspiration (Anderson, 2006; Wilson et al., 2005). However, while this might not be relevant to participants in the current study, it could explain why some men initially decided not to attend the screening. The ability to appraise a situation as something positive is based on individual experiences, personality or the ability to tolerate uncertainty (Brashers & Hogan, 2013; Carleton et al., 2007). In the current study, the participants often mentioned that they "were not the kind of person" that was bothered or worried about diseases such as an AAA. This mindset might be related to a personality trait, which—according to Hampson and Friedman (2008)—can affect how individuals react regarding their health, which can ultimately impact health outcomes.

The men were satisfied with the information received, both oral and written from the health care professionals. This might be related to the fact that some men and their partners continued to live as they did before AAA diagnosis and only took notice of it when it was time for the next follow-up. This is in line with Mishel (1990) description of uncertainty as a natural and fundamental part of our lives. With support from health care providers, the abilities described when appraising uncertainty as an opportunity could be considered a goal to strive for among those with a life-threatening illness. Mishel (1988) argued that a person's ability to process information refers to their cognitive capacity. If a person has the opportunity to improve the structure of their cognitive framework, it can reduce their experiences of uncertainty. Therefore, interventions have previously focused on improving cognitive capacity for patients living with various illnesses. Interventions with effects on social support, health behaviour and health education have been evaluated as successful and demonstrated benefits in reframing cancer knowledge (Bailey et al., 2004; Gil et al., 2006). Notably, this has been observed for cancer patients under both ongoing surveillance programmes and long-term follow-ups. Uncertainty management interventions have also been shown to reduce depression and anxiety while improving QOL for patients with lung cancer (Jiang & He, 2012). This implies that similar types of interventions might also be applicable and useful for participants attending AAA screening surveillance. However, there remains a need of further elaboration and modification of interventions to suit participants with AAAs.

5.2.3 Adjustment to life with an AAA diagnosis

Whether the situation was viewed as an opportunity or as a danger, the participants had to balance and adjust to a new life situation—a situation of being aware of an AAA diagnosis. This scenario might have been more stressful and impactful for participants that appraised the situation as a danger. As shown in the literature review chapter, the men attending surveillance programmes for AAAs had impacts on the QOL; however, it was difficult to conclude that this depended on an awareness of their AAA diagnosis alone (Ericsson et al., 2019). It was especially difficult for the partners to understand why the health care professionals mentioned that they should continue to live as they did before. For them, it was important to do what they could to stop AAA progression. Therefore, it was important for the partners to support and encourage the men to achieve a healthier lifestyle. It has previously been highlighted that encouragement and help from partners had a positive impact on patients suffering from cardiac disease adopting a new lifestyle (Martire et al., 2010). However, the men's appraisal of their partners' support in this study remained somewhat unclear. The men experienced this support as frustrating despite knowing that their partners only wanted what was best for them. A similar result was observed by Dalteg et al. (2011), who described the partners of patients with cardiac failure as overprotective regarding lifestyle changes, which negatively affected those suffering from the disease. Discussing lifestyle changes was a sensitive topic, which the partners in the present study were fully aware of. Therefore, they opted to avoid discussing them and attempted to accept men's lifestyle choices. It has been observed that discussing lifestyle changes as a couple can be difficult and include an involuntary imbalance of control, criticism and unbalanced power in the relationship. Notably, this can even be interpreted as a form of disrespect towards each other (Goldsmith et al., 2006). In the present study, it can also be assumed that part of this frustration was related to uncertainties in how lifestyle changes impact AAA progression. Moreover, this lack of knowledge regarding the effects of lifestyle changes in AAA patients has previously been noted in a qualitative interview study (Holmström et al., 2019). Therefore, this lack of clear advice and support might have led to different intentions regarding lifestyle changes between the men and their partners in this study. However, according to the health care professionals in the current study, they tried to follow up on the advice of smoking cessation when the men came for follow-ups. Apart from giving this advice, they did not provide any further support for smoking cessation. Existing evidence suggests that smoking cessation interventions would be cost-effective among men with screening-detected AAAs and could reduce the need for elective surgery (Bohlin et al., 2014). Moreover, a nurse-led smoking cessation intervention for patients with cardiac failure has been reported as successful since it covered both an assessment and education regarding risk factors, behaviour, lifestyle, tobacco use and health beliefs (Wood et al., 2008). This further indicates the need to develop and tailor effective smoking cessation interventions for men with AAAs while providing support and advice for lifestyle changes in a way that minimises emotional impacts for couples.

The partners took responsibility for the men's health, relieved them from heavy physical workloads and cared for them. It can be assumed that they felt not only anxious but also burdened by the sense of responsibility for the men's health considering the risk of AAA rupture. This implies that the partners also needed to adapt to a more restricted life in parallel to striving towards normality. Striving for a balance between normality in life and accepting a life with limitations has been recognised among couples after myocardial infarction. Notably, an independent lifestyle in combination with feeling secure has been highlighted as important (Kristofferzon et al., 2007). Another study showed that patients redefined normality in life after myocardial infarction (Tobin, 1996). Furthermore, it has previously been concluded that if couples are afflicted by a chronic illness, being physically and socially active has a positive impact on their QOL (Greeff, 2001). Maintaining or improving the QOL for participants living with an AAA should thus be considered a goal for professionals within the screening context.

5.3 Discussion of methodological considerations and limitations

This study used a single QCS design with embedded units since the purpose was to explore and describe perspectives of screening-detected AAA from the perspectives of diagnosed men, their partners and health care professionals. It contributed to a deeper understanding of their experiences and perspectives, which are of interest to nursing and health care professionals within the screening context. The QCS is a commonly used qualitative research method when the purpose is to obtain a deeper understanding of a phenomenon in a real-life context (Crowe et al., 2011; Stake, 1995; Yin, 2016). Furthermore, it facilitates comparisons between the units in the study (Darke et al., 1998). Therefore, the contrasts between the embedded units found in the results can highlight and improve our understanding of their differences and similarities. This understanding can be used to address the needs of the participants and indicate further clinical implications, such as support and education for the participants in this study.

Although QCS is a useful method for studying a phenomenon, it has been said to lack rigour (Jensen & Rodgers, 2001; Yin, 2018) because it is difficult to validate the rigour throughout the entire research process. Moreover, the use of different methods to collect and analyse data can complicate the validation of rigour (Gustafsson, 2017) However, throughout the entirety of the present study, efforts were made to enhance its rigour, which was assessed using the four concepts credibility, dependability, confirmability and transferability ((Lincoln & Guba, 1985).

The men in the QCS were purposefully selected from a screening database and the partners were recruited through a convenient sampling after obtaining consent from the men. This resulted in variation among the characteristics and demographic variables. For example, there were participants of different age, educational level, lifestyle and AAA size from both rural and urban areas. Despite the purposefully selected participants and increased number of foreign-born inhabitants in the southern part of Sweden, they were still underrepresented in the current study. Foreign-born persons generally have lower compliance with screening, which made them difficult to include in the current study. However, it can be questioned whether their lower compliance with screening is related to language difficulties or other cultural/social reasons. This can be seen as a limitation of the study that might impact its transferability. However, it has generally been difficult to recruit foreign-born individuals and minorities for nursing research (Knobf et al., 2007). It can be assumed that the sample of health care professionals was representative of the Swedish screening service, even though the demographic variation was not very wide.

One reason for conducting a QCS is to understand the studied phenomenon in a real-life context; thus, a deep description of the context is of utmost importance (Baxter & Jack, 2008; Stake, 2005; Yin, 2018). Such descriptions can allow readers to determine the transferability of a study to other similar contexts and situations. While transferability can be difficult to accomplish, since the context and participants of the present study have been described in detail, it can be assumed that its results can be used to develop care for patients and their partners in similar domestic and international screening contexts.

After the 12 first interviews with the partners, redundancy in the data was still not reached; therefore, partners were recruited through men that the PhD candidate had not met via an individual interview. This was considered an alternative method of reaching data saturation. The familiarity created with the men helped during the interviews with their partners; however, this aspect was missing from the additional interviews. Nevertheless, evading leading questions about the men's health and relying on interview guides minimised this influence in the collected data. The interview locations were chosen by the participants to make them feel as comfortable as possible and facilitate the sharing of their experiences. The amount of time available for the interviews allowed the participants and interviewer to become familiar with each other and increased the participants' feelings of confidence, which can strengthen their credibility.

All of the interviews were conducted and transcribed by the PhD candidate, which provided an opportunity to reflect on the interview techniques. Moreover, questions that were asked and followed in an inadequate way could be changed or replaced. This was especially true for questions that led to "yes" or "no" replies but was also true for those that primarily focused on the medical diagnosis and status.

As in all qualitative studies, reflexivity is central and strategies to reflect on the researcher's pre-understanding of the research area, background and characteristics are of critical importance since the researcher is the main instrument for both data collection and analysis (Miles et al., 2013). As a registered nurse with work experience in the vascular and anaesthesia fields, the pre-understanding of the PhD candidate may have impacted the data. Therefore, continuous discussions on this topic with her supervisors were of utmost importance for reflections. Furthermore, the supervisors contributed with strategies and support to allow the PhD candidate to reflect on whether the questions and the process of the analysis were based on a pre-understanding or the data itself. These discussions can be seen as a strength and decrease the risk of bias. Conversely, the pre-understanding of the researcher may also make it easier to understand the context as well as the experiences expressed during the interviews. The researcher's pre-understanding may have also helped the participants further develop their responses. Moreover, to address the issue of reflexivity, written memos were used for reflections throughout the entire research process—especially during data collection and analysis. The translated memos can also strengthen the credibility of the findings. Credibility is further ensured through the translated quotes incorporated throughout the results chapter (Chapter Four). Due to the high number of willing participants that wanted to contribute their experiences, a total of 46 individual interviews were conducted and used for the analysis. While there is no specific rule related to the sample size for qualitative studies, however the number of interviews were considered sufficient since no further information was identified in the preliminary analysis and in the final interviews. The purpose of conducting qualitative research is partly to reach a deeper understanding of a phenomenon. This study presents a deeper knowledge of the participants' perspectives and experiences of living with an AAA.

It has previously been argued that the analysis of QCSs requires further development (Baxter & Jack, 2008; Yin, 2018), which leaves the researcher to organise and decide on which approach is the most applicable. However, this represents a general limitation of the QCS method. According to Dubois and Gadde (2002), handling intertwined and interrelated elements in the analysis of a QCS is a challenge. Therefore, a modified QCA approach was used when analysing the data for the conducted QCS. This modified analysis approach was developed solely by the PhD candidate and then adjusted after discussions with her supervisors. The main reason for conducting the analysis for the partners' data and using this as an organisational frame for the men was the lack of research on the experiences of partners living with men that have a screening-detected AAAs and that studies focusing on men's experiences within AAA screening in the Swedish context have previously been published. Furthermore, since the completion of the conducted literature review (chapter two) additionally two articles within the "AAA Swedish screening context" have been published (Holmström et al., 2019; Pettersson et al., 2017). The labelled categories in the partners' analysis were used as an organisation frame. After the careful reading of and reflection on the data for men, it was determined that the three aforementioned categories fit this data. Since a QCS analysis should be considered one "unit of analysis" (Miles et al., 2013), the adopted approach enabled the organisation of data to describe its results within the embedded units. Furthermore, this well-organised data became a strength during the cross analysis between the embedded units. However, according to Miles and Huberman (1994), using a pre-structured approach for analysis can lead to the 'blindness' of data. However, we acknowledge that there is a potential risk that the interpretation of the data can be affected by researchers' existing understanding of previously analysed data from the partners. To minimise this risk, the PhD candidate constantly moved back and forth between the chunks and transcripts to ensure that the descriptions of the men's experiences evolved from the data despite it being organised under the same labelled categories as the partners. Memos and interpretations were also written down. This made it easier to determine and follow when the chunks from the data on men were highlighted, which is a recommendation for conducting both inductive and deductive qualitative analyses (Baxter & Jack, 2008; Gray et al., 2017; Miles et al., 2013).

5.4 Chapter summary

This chapter presented a discussion of how the study findings align with relevant literature and theories covering the research area. The concept of uncertainty is a recurring concept discussed in this chapter that might need to be given further attention within the AAA screening population. The differences in the participants' experiences also indicate the need for further improvements and potential clinical interventions. The next chapter presents the conclusions of the present study, the implications for clinical practice and recommendations for future studies.

CHAPTER SIX

IMPLICATIONS & CONCLUSIONS

6.1 Introduction

The final chapter of the thesis will present the implications for clinical practice, recommendations for future studies within the AAA screening field and the conclusions of the conducted QCS.

6.2 Recommendations

Through the QCS, a deeper understanding of the men's and the partners' experiences and perspectives on living with a screening-detected AAA was provided. Furthermore, health care professionals' experiences in caring for these men and their partners were presented. The differences between the men and their partners can illustrate unmet needs, which can provide valuable knowledge to support improved recommendations for clinical practice and care interventions. Additionally, new concepts and theories came to light during this QCS that require further research attention.

6.2.1 Recommendations for clinical practice

The findings of this study can enhance the care for participants (both men and their partners) living with an AAA. Notably, the overall findings support the need for further clinical improvements.

To develop and improve clinical practice for participants in the AAA screening context, it is evident that additional resources and educational initiatives are required. Moreover, time should be set aside for professionals to actively develop care while also meeting individuals' needs for care and support. This study identified various perspectives on and experiences of adjusting to life with an AAA diagnosis. To meet individuals' unique needs for sufficient information, education and support, their care must be individually tailored and available. However, there is also a need to continue and increase the national interdisciplinary collaboration between health care professionals working in AAA screening. This would ensure that screening participants receive similar information and care nationwide while minimising national variation in the screening context to achieve equal health care.

The findings of this study highlighted a lack of knowledge regarding the reasons for AAA development and progression. Although health care professionals tried to provide patients with important information, it was revealed that the participants perceived a restriction of information after the first screening. This indicates the need to develop new routines for providing participants with information. As stated in the results section, some clinics send home written information for the men and their partners to read at home. A well-organised booklet with relevant information might increase knowledge about AAAs among participants.

Another solution that could improve patient care and provide adequate patient- and diagnosis-oriented information is the further development of e-health methods for AAA participants attending regular follow-ups. Notably, e-health is a broad concept defined by the WHO guidelines as "the use of information and communications technology in support of health and health-related fields" (WHO Recommendations on Digital Interventions for Health System Strengthening, 2019, p. IX). Over the past couple of years, e-health has increased with the advent of new technology. It has been developed for medical and health care services, which has resulted in the enhancement of medical care (Barello et al., 2016). An e-health tool was recently developed for this cohort and has been evaluated as acceptable for use by the users (Nilsson et al., 2020). However, further improvements and implementations are required before reaching out to the diagnosed men and their family members. Other enhancements of the e-health application include a focus on solutions, where the users can obtain feedback on questions or concerns raised with their health care providers.

While e-health tools and web platforms can increase the availability of adequate information and care, they can never replace physical consultations and face-to-face meetings between the health care professionals and the participants. It was revealed that the diagnosed men in this study did not want to bother their family members and partners with adverse impacts related to the disease. Furthermore, among men in their 60s with prostate cancer, more than one out of five men in Sweden did not have anyone to share their emotions and concerns with (Helgason et al., 2001). This result indicates the dire need for Swedish health care professionals to take an active role and equip the health care service to address the emotional support required for this cohort.

The present study also revealed that partners need to be actively involved in the care of men diagnosed with an AAA. While the development of formal routines to address this need are requested, an alternative strategy could involve providing affected couples with a contact nurse. The implementation of a contact nurse was also considered by the health care professionals in the current study as an alternative method of increasing continuity during the screening surveillance. Also, being available to meet the participants’ needs when they arose might help them to understand their reactions and the impacts of the diagnosis on their lives. However, the role of a contact nurse within the vascular field still seems relatively undefined. Therefore, contact nurses’ commitments and responsibilities must first be identified and defined. However, based on experiences from cancer care, there are different strategies to organise health care for contact nurses to improve support for patients and their families (Bjuresäter & Larsson, 2017). It has been highlighted that contact nurses should have "in-depth knowledge" and the ability to educate, inform, support and guide patients and their families through the clinical pathway (Westman et al., 2018). In addition to contact nurses, practices that actively encourage partners to join during both screening examinations and medical consultations need to be developed. This would provide support for the men while also providing their partners with the opportunity to meet the health care professionals and raise their questions and concerns with them directly.

Smoking cessation is a solution that can decrease the risk of AAA expansion while also preventing AAA ruptures and their negative consequences (Wanhainen et al., 2019). However, insights from participants' experiences in this study highlighted concerns regarding a lack of knowledge on the impact of lifestyle changes for those diagnosed with an AAA. Apart from merely giving advice and information, there is also a need to develop, modify and justify lifestyle interventions to make them suitable for participants in the AAA screening context. Notably, vascular nurses need to take an active role in the development of these interventions. Such interventions should include lifestyle assessments, education about risk factors and risky behaviour as well as a coordinated and supported smoking cessation programme. This could also imply that vascular nurses require further education and training, e.g., in motivational interviewing and behaviour change. It is reasonable that the primary focus should be on smoking cessation. However, other lifestyle changes, e.g., physical exercise and diet changes can have positive secondary outcomes for both general health and AAAs. The involvement of partners is highly relevant in terms of lifestyle impacts on AAAs and supporting their AAA-diagnosed partners in general. It has been observed that support from family members during lifestyle changes increases the likelihood of success (Martire et al., 2010).

6.2.2 Recommendations for future research

The ongoing project of improving the information provided in the AAA screening invitation is very important. However, the purpose of developing both clinical guidelines and information is to optimise the context and care for patients (Armstrong et al., 2018). The involvement of patients in the development process of patient-related information has been evaluated as effective and highly recommended (Graham, 2011). Therefore, the development of future collaborations with participants living with an AAA must first be established. It is hoped that such collaboration can enhance the information provided in the AAA screening invitation and other forms of patient-related information to further increase the comprehensibility, acceptability and readability for the men and the partners.

Furthermore, it might be reasonable to collaborate on a national level to standardise the information available to participants at all screening centres.

The presence of uncertainty is certain among the participants with a screening-detected AAA and their partners. This indicates the need for interventions to reduce experiences of uncertainty. For example, previous interventions to manage and appraise uncertainty as an opportunity instead of a danger in a population with a chronic illness focused on improving their cognitive capacity (Bailey et al., 2004; Gil et al., 2006) related to the disease.

According to the uncertainty in illness theory (Mishel, 1988), improved cognitive capacity can decrease uncertainty, which can subsequently impact psychological and QOL outcomes as well as adjustment to diseases. Although educational support and available information have been evaluated among cancer patients (Bailey et al., 2004; Gil et al., 2006), these kinds of interventions need to be modified for AAA screening patients, who can be under surveillance with continuous follow-ups for a long time. Additionally, to develop information and educational initiatives for participants in the screening context, it might be essential to evaluate the participants' health literacy and perceptions of the disease as a first step in future studies. Furthermore, according to Mishel (1988), trust in the health care system and its professionals, which is mentioned as the "credible authority", can decrease the risk of uncertain experiences. The goal for health care professionals is to reduce experiences of uncertainty among participants. Notably, the clinical implementation of a contact nurse to meet individuals' needs would hopefully increase the "credible authority" while decreasing uncertainty. However, future studies are needed to evaluate the effect of a contact nurse among the participants in terms of both the presence of uncertainty and the psychosocial impacts on life. The Mishel Uncertainty Illness Scale - Community form (MUIS-C) (Mishel & Epstein, 1997) is an instrument based on Mishel's theory (Mishel, 1988) of uncertainty in illness. This is a generic instrument, which means that it can be applied to a variety of populations. Notably, this instrument has previously been tested and used in the Swedish context (Bolse et al., 2002). The MUIS-C may be suitable for use in the AAA population to evaluate interventions aimed at reducing the level of uncertainty.

Appraising uncertainty as a danger might impact patients' psychological outcomes when adjusting to life with an AAA. Most existing studies have used general QOL instruments when appraising non-medical outcomes for living with a screening-detected AAA diagnosis. While QOL is important, it might not capture impacts on participants with an AAA diagnosis. Therefore, there remains a need to develop a reliable condition-specific instrument to assess the psychosocial impact of AAA diagnosis and being under continuous surveillance. Furthermore, the appraisal of psychosocial impacts also needs to be extended in future evaluations to include partners living with an awareness of their spouse's AAA diagnosis.

The clinical implications of the lifestyle interventions mentioned in the previous subsection require further systematic and scientific evaluation. For example, it will be necessary to evaluate whether a nurse-led smoking cessation intervention affects the AAA expansion when compared to normal smoking cessation advice. Furthermore, other valuable secondary cardiovascular outcomes can be evaluated, such as blood pressure, lipid levels, exercise scores and dietary scores. The nurse-led interventions need to be operated over a long time and evaluated over this period. Notably, it has been observed that personality traits affect smoking cessation rates among patients that had a myocardial infarction. Patients with weaker personality traits (e.g., agreeableness) more often continued to smoke than those with a stronger personality traits (Schlyter et al., 2016). Furthermore, a persons' self-efficacy and self-management might be relevant to health care professionals when predicting outcomes and creating individualised adaptations within the framework of a smoking cessation programme.

6.3 Conclusion

In conclusion, this QCS increases our knowledge and provides further insights into the experiences and perceptions of living with a screening-detected AAA diagnosis from the perspectives of diagnosed men and their partners. Furthermore, this study also described how health care professionals experience caring for the diagnosed men and their partners. The contrasts of how participants experienced the awareness of the AAA diagnosis were also presented in this thesis. Notably, these findings are of interest to the nursing field, health care professionals working in the screening context and the health care service providing resources within this sector.

Awareness of an AAA diagnosis detected through screening affected men as well as the partners. A range of experiences that influenced the participants' lives was described. However, it was evident that this diagnosis impacted their lives either during certain situations or constantly. This diagnosis also resulted in different degrees of worry among the partners, who were mainly concerned about AAA rupture risk. While the degree of worry could be discerned among the men, it was not as evident as that of their partners.

Screening surveillance represents an ongoing process from the first screening examination and diagnosis towards an adjustment to the new situation of accepting the AAA diagnosis. This was interpreted as a screening surveillance journey. These journeys varied considerably among the interviewed men in terms of the impact they had on their lives. Since the men attended a screening surveillance programme and were continuously followed up via U/S, it made their experiences recurrent. Although the health care professionals were aware that AAA diagnosis impacted the participants' life situations, certain discrepancies in their perceptions of how this diagnosis affected participants' lives and care were identified.

This study also revealed that the participants had concerns regarding the causes of AAAs and the treatment. Moreover, it was determined that their main concerns were related to AAA rupture risk. Notably, these components and concerns are related to uncertainty. To manage life with an AAA and adjust to the inherent uncertainty of this life-threatening disease, certain interventions are required. The results of this thesis are essential to further tailoring and developing relevant future interventions.

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APPENDIX

Appendix 1: Information sheet: Study of men who have a screening-detected abdominal aortic aneurysm, their experiences and need for further support

As participants of the screening programme for abdominal aortic aneurysm at Kärlcentrum in Malmö, you are invited to participate in the aforementioned study.

The knowledge of having an abdominal aortic aneurysm can affect life in different ways. Therefore, an interview study will be introduced to evaluate the impact it might have on quality of life. The study will, for example, evaluate whether patients' lifestyles have changed and whether further support might help to handle the situation of living with an abdominal aortic aneurysm. As a participant of the screening programme, you are thus welcome to participate in this study.

The interview will take approximately 30–60 minutes. We offer a place to conduct the interview. Alternatively, you may decide on a place and time for the interview. With your consent, we would like to record the interview. Interview data will be kept anonymous and secure in the future. Participation in the study is voluntary and you have every right to withdraw before or during the study without any further consequences regarding your future care and contact with Kärlcentrum in Malmö. All information will remain confidential. The study is a part of a doctoral thesis.

If you would like to participate in the study, we kindly ask you to sign the response sheet and we will contact you to make an appointment for the interview. If you have further questions or want more information, you are most welcome to contact me or any of my supervisors.

Sincerely,

Anna Ericsson
PhD candidate, RN
Fakulteten för Hälsa och Samhälle
Malmö Högskola
Institutionen för Vårdvetenskap
anna.eriksson@

Christine Kumlien
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Elisabeth Carlson
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Malmö Högskola
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elisabeth.carlson@

(Cont. Appendix 1)

Response sheet

Study of men who have a screening-detected abdominal aortic aneurysm, their experiences and need for further support.

I would like to participate in this study. ☐

Please contact me at this phone number to arrange a time and place for the interview:

____

____

Signature, place and date

Please return to the following address using the prepaid envelope.

Anna Ericsson
Postfack F316
Fakulteten för Hälsa och Samhälle
Malmö Högskola
Jan Waldenströms gata 25
205 06 Malmö

(Cont. Appendix 1, Swedish version)

Studie om män med screening diagnostiserat kroppspulsåder bråck, deras upplevelser, erfarenheter och behov av ytterligare stöd

Som deltagare på screening programmet för bråck på stora kroppspulsådern, på Kärlcentrum i Malmö, tillfrågas Du om deltagande i ovanstående studie.

Vetskapen om att ha ett bråck på stora kroppspulsådern kan påverka livet på olika vis. Därför kommer en intervjustudie att påbörjas för att undersöka vilken påverkan det kan ha på livskvaliteten. Studien kommer också att undersöka hur det påverkar förändring av levnadsvanor och om hälso- och sjukvården kan bidra med stöd för att underlätta situationen av att leva med ett kroppspulsåderbråck. Du som går på screeningprogrammet välkomnas därför att delta i studien.
Intervjun beräknas att ta mellan 30-60 minuter. Vi erbjuder plats för intervjun alternativt att du själv föreslår plats. Med din tillåtelse skulle vi gärna vilja spela in intervjun på band. Inspelningen kommer att sparas inlåst så att ingen oberörd kan ta del av den.

Deltagandet är helt frivilligt och Du kan avbryta när som helst utan att ange någon orsak eller med några konsekvenser för Din behandling eller kontakt med Kärlcentrum. Resultaten av studien kommer att redovisas så att Du inte kan identifieras.

Studien ingår som en del av en doktorandutbildning.

Om Du vill delta i studien ber vi Dig att underteckna talongen och vi kommet att ta kontakt med dig för att bestämma plats och tid för intervjun.
Om Du har några frågor eller vill veta mer, är Du välkommen att kontakta någon av oss, antingen mig eller mina handledare.

Med vänlig hälsning

Anna Ericsson
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elisabeth.carlson@

(Cont. Appendix 1, Swedish version)

Svarsblankett

Studie om män med screening diagnostiserat kroppspulsåder bråck, deras upplevelser, erfarenheter och behov av ytterligare stöd

Jag vill gärna delta in studien ☐

Kontakta mig på följande telefonnummer för överenskommelse om tid och plats för

intervju____

____

Namn, ort och datum

Vänligen skicka svarsblanketten i bifogat kuvert till

Anna Ericsson
Postfack F316
Fakulteten för Hälsa och Samhälle
Malmö Högskola
Jan Waldenströms gata 25
205 06 Malmö

Appendix 2: Information sheet: Study of men who have a screening-detected abdominal aortic aneurysm, their experiences and need for further support (Reminder)

As participants of the screening programme for abdominal aortic aneurysm at Kärlcentrum in Malmö, you have recently been invited to the aforementioned study. This is a kindly reminder of your invitation.

The knowledge of having an abdominal aortic aneurysm can affect life in different ways. Therefore, an interview study will be introduced to evaluate the impact it might have on quality of life. The study will, for example, evaluate whether patients' lifestyles have changed and whether further support might help them handle the situation of living with an abdominal aortic aneurysm. As a participant at the screening programme, you are thus welcome to participate in the study.

The interview will take approximately 30–60 minutes. We offer a place to conduct the interview. Alternatively, you may decide on a place and time for the interview. With your consent, we would like to record the interview. Interview data will be kept secure in the future. Participation in the study is voluntary and you have every right to withdraw before or during the study without any further consequences regarding your future care and contact with Kärlcentrum in Malmö. All information will remain confidential. The study is a part of a doctoral thesis.

If you would like to participate in the study, we kindly ask you to sign the response sheet and we will contact you to make an appointment for the interview.
If you have further questions or want to have more information, you are most welcome to contact me or any of my supervisors.

Sincerely,

Anna Ericsson
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och Samhälle
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elisabeth.carlson@

(Cont. Appendix 2)

Response sheet

Study of men who have a screening-detected abdominal aortic aneurysm, their experiences and need for further support.

I would like to participate in this study. ☐

Please contact me at this phone number to arrange a time and place for the interview:

____

Signature, place and date

Please return to the following address using the prepaid envelope.

Anna Ericsson
Postfack F316
Fakulteten för Hälsa och Samhälle
Malmö Högskola
Jan Waldenströms gata 25
205 06 Malmö

(Cont. Appendix 2, Swedish version)

Studie om män med screening diagnostiserat kroppspulsåder bråck, deras upplevelser, erfarenheter och behov av ytterligare stöd

Som deltagare på screening programmet för bråck på stora kroppspulsådern, på Kärlcentrum i Malmö, blev du för ett tag sedan tillfrågad om deltagande till ovanstående studie, detta är en påminnelse.
Vetskapen om att ha ett bråck på stora kroppspulsådern kan påverka livet på olika vis. Därför kommer en intervjustudie att påbörjas för att undersöka vilken påverkan det kan ha på livskvaliteten. Studien kommer också att undersöka hur det påverkar förändring av levnadsvanor och om hälso- och sjukvården kan bidra med stöd för att underlätta situationen av att leva med ett kroppspulsåderbråck. Du som går på screeningprogrammet välkomnas därför att delta i studien.
Intervjun beräknas att ta mellan 30-60 minuter. Vi erbjuder plats för intervjun alternativt att du själv föreslår plats. Med din tillåtelse skulle vi gärna vilja spela in intervjun på band. Inspelningen kommer att sparas inlåst så att ingen oberörd kan ta del av den.

Deltagandet är helt frivilligt och Du kan avbryta när som helst utan att ange någon orsak eller med några konsekvenser för Din behandling eller kontakt med Kärlcentrum. Resultaten av studien kommer att redovisas så att Du inte kan identifieras.

Studien ingår som en del av en doktorandutbildning.
Om Du vill delta i studien ber vi Dig att underteckna talongen och vi kommet att ta kontakt med dig för att bestämma plats och tid för intervjun.
Om Du har några frågor eller vill veta mer, är Du välkommen att kontakta någon av oss, antingen mig eller mina handledare.

Med vänlig hälsning

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(Cont. Appendix 2, Swedish version)

Svarsblankett
Studie om män med screening diagnostiserat kroppspulsåder bråck, deras upplevelser, erfarenheter och behov av ytterligare stöd

Jag vill gärna delta in studien ☐

Kontakta mig på följande telefonnummer för överenskommelse om tid och plats för intervju____

____
Namn, ort och datum

Vänligen skicka svarsblanketten i bifogat kuvert till

Anna Ericsson
Postfack F316
Fakulteten för Hälsa och Samhälle
Malmö Högskola
Jan Waldenströms gata 25
205 06 Malmö

Appendix 3: Consent form for men

I have received the information regarding “Study of men who have a screening-detected abdominal aortic aneurysm, their experiences and need for further support”.

I acknowledge that my participation in the project is voluntary and that I can withdraw at any time without providing any reason and without any consequences for my own or my partner’s contact with the Kärlcentrum in Malmö.

I hereby consent to the interview being recorded.

Signature of participant	*Signature of the PhD candidate*
Place, date	Place, date
Signature	Signature
Telephone number	Telephone number

(Cont. Appendix 3, Swedish version)

Samtyckesblankett (män)

Jag har tagit del av informationen angående ” Studie om män med screening diagnostiserat kroppspulsåder bråck, deras upplevelser, erfarenheter och behov av ytterligare stöd”.

Jag har också tagit del av informationen att deltagandet är frivilligt och att jag kan avbryta när som helst utan att ange orsak eller med några konsekvenser för min eller min partners fortsatta kontakt med Kärlcentrum.

Härmed ger jag mitt samtycke till att bli intervjuad och att intervjun spelas in.

Underskrift av undersökningsperson	*Underskrift av doktorandstudent*
______________________________	______________________________
Ort, datum	Ort, datum
______________________________	______________________________
Underskrift	Underskrift
______________________________	______________________________
Telefonnummer	Telefonnummer

Appendix 4: Information sheet: Partners' experiences of living with a man that has a screening-detected abdominal aortic aneurysm

You are invited to participate in the aforementioned study.

Your partner has been diagnosed with an abdominal aortic aneurysm (AAA) and he is attending regular follow-ups at Skåne University Hospital in Malmö. The awareness of having a screening-detected AAA may impact those who are diagnosed. However, this awareness may also affect their family members. Therefore, the interview study will be conducted on this topic. Your experiences are important to consider in the evaluation of whether more support is needed for those living with a person diagnosed with an AAA.

We offer a place where the interview can be conducted. Alternatively, you may decide on a place and time for your interview. The interview will take approximately 30–60 minutes. With your consent, we would like to record the interview. The interview data will be kept anonymous and secure.

Participation is voluntary and you have every right to withdraw from the study before or during the study without any consequences for you, your partner and future contact with Kärlcentrum in Malmö. All information related to you will remain confidential.

The study is a part of a doctoral thesis.

If you would like to participate, we kindly ask you to sign the response sheet. If you have further questions, you are welcome to contact me or any of my supervisors.

Sincerely,

Anna Ericsson
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elisabeth.carlson@

(Cont. Appendix 4)

Response sheet

Partners' experiences of living with a man that has a screening-detected abdominal aortic aneurysm

I would like to participate in this study. ☐

Please contact me at this phone number to arrange a time and place for the interview:

____

____
Signature, place and date

Please send to the following address using the prepaid envelope.

Anna Ericsson
Postfack F316
Fakulteten för Hälsa och Samhälle
Malmö Högskola
Jan Waldenströms gata 25
205 06 Malmö

MALMÖ HÖGSKOLA

REGION SKÅNE

(Cont. Appendix 4, Swedish version)

Anhörigas upplevelser av att leva tillsammans med en partner med bråck på stora kroppspulsådern

Du tillfrågas om deltagande i ovanstående studie

Din partner har blivit screenad med ultraljud och diagnostiserad med ett bråck på stora pulsådern på Universitetssjukhuset i Skåne, Malmö.
Vetskapen om att ha ett bråck på stora kroppspulsådern kan påverka den drabbade personen såväl som övriga familjemedlemmar. Därav kommer en intervjustudie att inledas och vi inbjuder Dig som partner att delta i denna studie. Era upplevelser och erfarenheter är viktiga att ta hänsyn till för att utvärdera om ytterligare stöd kan behövas till dem som lever nära någon med bråck på stora kroppspulsådern.

Vi erbjuder plats för intervjun, alternativt att du själv föreslår plats och tidpunkt för intervjun. Intervjun beräknas att ta mellan 30–60 minuter. Med din tillåtelse skulle vi gärna vilja spela in intervjun på band. Inspelningen kommer att sparas inlåst så att ingen oberörd kan ta del av den.

Deltagandet är frivilligt och du kan när som helst dra dig ur studien utan påverkan för Dig eller Din partners vidare kontakt med Kärlcentrum i Malmö. All information som du bidrar med kommer att behandlas konfidentiellt.

Studien ingår som en del av en doktorandutbildning.

Om du vill delta ber vi dig underteckna talongen som medföljer till detta informationsblad.
Om du har några frågor eller vill veta mer är du välkommen att kontakta någon av oss, antingen mig eller min handledare.

Med vänlig hälsning

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elisabeth.carlson@

(Cont. Appendix 4, Swedish version)

Svarsblankett
Anhörigas upplevelser av att leva tillsammans med en partner med bråck på stora kroppspulsådern

Jag vill gärna delta in studien ☐

Kontakta mig på följande telefonnummer för överenskommelse om tid och plats för

intervju____

____
Namn, ort och datum

Vänligen skicka svarsblanketten i bifogat kuvert till

Anna Ericsson
Postfack F316
Fakulteten för Hälsa och Samhälle
Malmö Högskola
Jan Waldenströms gata 25
205 06 Malmö

Appendix 5: Information sheet: Partners’ experiences of living with a man that has a screening-detected abdominal aortic aneurysm (Reminder)

Recently, you were asked to participate in the aforementioned study. This is kindly reminder of your invitation.

Your partner has been screened with ultrasound and diagnosed with an abdominal aortic aneurysm at the Skåne University Hospital in Malmö.

The knowledge of having an abdominal aortic aneurysm may affect the diagnosed people as well as their family members. Therefore, an interview study will be introduced to address this concern. We would like to invite you as a partner to participate in this study. Your experiences are important in evaluating whether further support is needed for those who live with a person that has an abdominal aortic aneurysm.

We offer a place for the interview. Alternatively, you may suggest a place and time for the interview. The interview takes approximately 30–60 minutes. With your consent, we would like to record the interview. Interview data will remain secure so that no one can read or listen to it. Your participation is voluntary and you have the right to withdraw at any time without any consequence for you or your partner’s future contact with Kärlcentrum. All information related to you will remain confidential. The study is a part of a doctoral thesis.

If you would like to participate, we kindly ask you to sign the consent form. If you have further questions or would like to know more about the study, please do not hesitate to contact me or any of my supervisors.

Sincerely,

Anna Ericsson
PhD candidate, RN
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anna.eriksson@

Christine Kumlien
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Elisabeth Carlson
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Malmö Högskola
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elisabeth.carlson@

(Cont. Appendix 5)

Response sheet

Partners' experiences of living with a man that has a screening-detected abdominal aortic aneurysm

I would like to participate in this study. ☐

Please contact me at this phone number to arrange a time and place for the interview:

____

____
Signature, place and date

Please return to the following address using the prepaid envelope.

Anna Ericsson
Postfack F316
Fakulteten för Hälsa och Samhälle
Malmö Högskola
Jan Waldenströms gata 25
205 06 Malmö

(Cont. App 5, Swedish version)

Anhörigas upplevelser av att leva tillsammans med en partner med bråck på stora kroppspulsådern

För ett tag sedan tillfrågades du om deltagande i ovanstående studie, detta är en påminnelse.

Din partner har blivit screenad med ultraljud och diagnostiserad med ett bråck på stora pulsådern på Universitetssjukhuset i Skåne, Malmö.
Vetskapen om att ha ett bråck på stora kroppspulsådern kan påverka den drabbade personen såväl som övriga familjemedlemmar. Därav kommer en intervjustudie att inledas och vi inbjuder Dig som partner att delta i denna studie. Era upplevelser och erfarenheter är viktiga att ta hänsyn till för att utvärdera om ytterligare stöd kan behövas till dem som lever nära någon med bråck på stora kroppspulsådern.
Vi erbjuder plats för intervjun, alternativt att du själv föreslår plats och tidpunkt för intervjun. Intervjun beräknas att ta mellan 30–60 minuter. Med din tillåtelse skulle vi gärna vilja spela in intervjun på band. Inspelningen kommer att sparas inlåst så att ingen oberörd kan ta del av den.

Deltagandet är frivilligt och du kan när som helst dra dig ur studien utan påverkan för Dig eller Din partners vidare kontakt med Kärlcentrum i Malmö. All information som du bidrar med kommer att behandlas konfidentiellt.

Studien ingår som en del av en doktorandutbildning.
Om du vill delta ber vi dig underteckna talongen som medföljer till detta informationsblad.
Om du har några frågor eller vill veta mer är du välkommen att kontakta någon av oss, antingen mig eller min handledare.

Med vänlig hälsning

Anna Ericsson
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elisabeth.carlson@

(Cont. Appendix 5, Swedish version)

Svarsblankett
Anhörigas upplevelser av att leva tillsammans med en partner med bråck på stora kroppspulsådern

Jag vill gärna delta in studien ☐

Kontakta mig på följande telefonnummer för överenskommelse om tid och plats för

intervju____

____

Namn, ort och datum

Vänligen skicka svarsblanketten i bifogat kuvert till

Anna Ericsson
Postfack F316
Fakulteten för Hälsa och Samhälle
Malmö Högskola
Jan Waldenströms gata 25
205 06 Malmö

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Appendix 6: Consent form for partners

I have received the information regarding the study about partners' experiences of living with a man that has a screening-detected abdominal aortic aneurysm.

I acknowledge that my participation in the project is voluntary and that I can withdraw at any time without providing any reason and without any consequences for my own or my partner's contact with Kärlcentrum in Malmö.

I hereby consent to participate in the interview and for the interview to be recorded.

Signature of the participant	*Signature of the PhD candidate*
Place, date	Place, date
Signature	Signature
Telephone number	Telephone number

(Cont. Appendix 6, Swedish version)

Samtyckesblankett

Jag har tagit del av informationen om ” Anhörigas upplevelser av att leva tillsammans med en partner med bråck på stora kroppspulsådern”.

Jag har också tagit del av informationen att deltagandet är frivilligt och att jag kan avbryta när som helst utan att ange orsak eller med några konsekvenser för min eller min partners fortsatta kontakt med Kärlcentrum, Malmö.

Härmed ger jag mitt samtycke till att bli intervjuad och att intervjun spelas in.

Underskrift av undersökningsperson	*Underskrift av doktorandstudent*
Ort, datum	Ort, datum
Underskrift	Underskrift
Telefonnummer	Telefonnummer

Appendix 7: Consent from men to contact their partners

This letter has been sent to you because you are under surveillance with regular follow-ups for an abdominal aortic aneurysm at Kärlcentrum in Malmö.

It has previously been shown that the knowledge of having an abdominal aortic aneurysm affects life in different ways for the diagnosed person. However, this knowledge may also affect the person's family members. Therefore, an interview study has been started with partners to men under surveillance in order to evaluate their partners' experiences.

Therefore, we would like to ask for your consent to contact and invite your partner to the study.

If you agree, we kindly ask you to return the response sheet with your partner's name and your signature. Thereafter, an information letter about the study with an invitation will be sent to your partner.

If you have any questions or want to know more, you are welcome to contact me or any of my supervisors.

Sincerely,

Anna Ericsson
PhD candidate, RN
Fakulteten för Hälsa
och Samhälle
Malmö Högskola
Institutionen för
Vårdvetenskap
anna.eriksson@

Christine Kumlien
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Vårdvetenskap
elisabeth.carlson@

(Cont. Appendix 7)

Response sheet

I hereby consent to contact my partner. ☐

My partner’s name: ____

____

Signature, place and date

Please return to the following address using the prepaid envelope.

Anna Ericsson
Postfack F316
Fakulteten för Hälsa och Samhälle
Malmö Högskola
Jan Waldenströms gata 25
205 06 Malmö

(Cont. Appendix 7, Swedish version)
Samtycke från männen att kontakta deras partners

Detta brev skickas till dig som går i uppföljning för bråck på stora kroppspulsådern, på Kärlcentrum i Malmö.

Tidigare forskning har belyst hur kännedom om att ha ett bråck på kroppspulsådern kan påverka livet på olika vis för den drabbade personen. Denna kunskap kan även påverka övriga familjemedlemmar. Därav har en intervjustudie påbörjats med partners till män som deltar på screeningprogrammet för att undersöka partnerns upplevelser, erfarenheter och behov av eventuellt stöd. Vi skulle därför vilja tillfråga dig om tillåtelse att kontakta din partner för inbjudan till denna studie. Om du samtycker ber vi dig skicka in svarsblanketten med din partners namn samt din underskrift så kommer ett informationsbrev och inbjudan skickas direkt till din partner.

Om du har några frågor eller vill veta mer är du välkommen att kontakta någon av oss, antingen mig eller någon av mina handledare.

Med vänlig hälsning

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elisabeth.carlson@

(Cont. Appendix 7, Swedish version)

Svarsblankett

Ni har min tillåtelse att tillfråga min partner om deltagande i studien ☐

Min partners namn: ____

____
Namn, ort och datum

Vänligen skicka svarsblanketten i bifogat kuvert till

Anna Ericsson
Postfack F316
Fakulteten för Hälsa och Samhälle
Malmö Högskola
Jan Waldenströms gata 25
205 06 Malmö

Appendix 8: Information sheet: Focus group interviews with health care professionals working with AAA screening

To Whom it May Concern:

My name is Anna Ericsson, a PhD candidate at Malmö University/The Hong Kong Polytechnic University. My field of research is aortic screening patients. I have received your contact information from Anders Gottsäter (Professor and Medical Doctor) at Kärlcentrum Skåne University Hospital, Malmö.

I am contacting you because we wish to connect with medical doctors and nurses involved in the screening programme for abdominal aortic aneurysm at your clinic and further invite them to a focus group interview. Clinical experience of caring for patients with screening-diagnosed abdominal aortic aneurysm (AAA) and their relatives will be the basis for the discussion. The purpose is to elucidate the care and support that patients and their relatives may require from a clinical perspective. The discussion is expected to take 60–90 minutes depending on how many participate in the discussion. Participation is voluntary.

I would be grateful if you could assist me with further contact information to invite and plan for the discussion.

Thanks in advance,

Sincerely,
Anna Ericsson
Anna.eriksson@[redacted]
0706-37[redacted]

(cont. Appendix 8 Swedish version)

Fokusgrupp intervjuer med AAA-screening personal

Hej,

Mitt namn är Anna Ericsson och jag är doktorand vid Malmö Högskola. Min forskarinriktning är aortascreening patienter. Dina kontaktuppgifter har jag fått av Anders Gottsäter, Kärlcentrum SUS.
Jag skriver till dig för vi vill komma i kontakt med läkare och sjuksköterskor som är delaktiga i screeningverksamheten för aorta aneurysm på er klinik för att bjuda in er till en fokusgrupp intervju. Klinisk erfarenhet av att vårda patienter med screening diagnostiserat AAA och deras anhöriga kommer att ligga som grund för diskussionen. Syftet är att utifrån ett kliniskt perspektiv belysa vård och stöd som patienterna och deras närstående kan vara i behov av. Diskussionen beräknas att ta mellan 60-90 minuter beroende på hur många det blir i gruppen och deltagandet är helt frivilligt.

Jag vore tacksam om du kan bistå mig med vidare kontaktuppgifter för fortsatt planering och inbjudan.

Tack på förhand,

Vänliga Hälsningar,
Anna Ericsson
Anna.eriksson@
0706-37

MALMÖ HÖGSKOLA

REGION SKÅNE

Appendix 9: Information for the participants of the focus group interviews

Focus group interviews regarding men with screening diagnosed aortic aneurysm, their experiences of care and any need for additional support.

As a health care professional working with screening for AAA at … (the clinic), you are invited to participate in a focus group discussion. Your experiences of caring for these patients and their relatives will partly be the basis of the discussion. Additional focus will also be placed on preliminary results from individual interviews with the men and their partners. The purpose of the group discussion is to highlight, from your perspective, the care and support that the patients and their relatives may require.

The focus group discussion will take place on … (date, time, place) together with other staff who are involved in the screening activities. Any information you contribute will be treated confidentially.

If you have any questions, you are welcome to contact me at anna.eriksson@ .

The focus group discussion is included as part of a doctoral programme.

Kind regards,

Anna Ericsson
PhD candidate, RN
Fakulteten för Hälsa och Samhälle
Malmö Högskola
Institutionen för Vårdvetenskap
anna.eriksson@

Christine Kumlien
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elisabeth.carlson@

(Cont. Appendix 9, Swedish version)

Fokusgrupp intervjuer angående män med screening diagnostiserat aorta aneurysm, deras upplevelser av vården och eventuella behov av ytterligare stöd.

Som personal på screeningprogrammet för aorta aneurysm på kliniken …..inbjuds du att delta i en fokusgrupp diskussion. Er erfarenhet av att vårda dessa patienter och deras närstående kommer delvis ligga som grund i diskussionen, men även preliminära resultat från individuella intervjuer med männen samt deras partners. Syftet är att utifrån ert perspektiv belysa vård och stöd som patienterna och deras närstående kan vara i behov av.

Fokusgrupp diskussionen kommer att äga rum på arbetstid den…. på ….med blandade arbetskategorier delaktiga i screeningverksamheten. Diskussionen beräknas ta 60-90 minuter. Deltagandet är frivilligt och all information som du bidrar med behandlas konfidentiellt.

Vid intresse för att deltaga ber vi dig underteckna talongen som medföljer alternativt maila ditt svar till anna.eriksson@ .

Fokusgrupp diskussionen ingår som en del av en doktorandutbildning.
Om du har några frågor är du välkommen att kontakta någon av oss.

Med vänlig hälsning

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elisabeth.carlson@

(Cont. Appendix 9, Swedish version)

Svarsblankett

Jag deltar gärna i fokusgrupp diskussionen ☐

Namn, ort och datum

Email/ alternativt telefonnummer

Vänligen skicka svarsblanketten i bifogat kuvert till

Anna Ericsson
Postfack F316
Fakulteten för Hälsa och Samhälle
Malmö Högskola
Jan Waldenströms gata 25
205 06 Malmö

Appendix 10: Interview guide for men living with a screening-detected AAA

(Swedish version)

Intervjufrågor män med abdominellt aorta aneurysm

Introduktion

- Syftet med studien
- Del av ett doktorand projekt
- Intervjuerna kommer att spelas in med deltagarnas tillåtelse
- Det är frivilligt att delta och varje enskild har rätt att dra sig ur studien när som

Öppnings fråga

- Kan du berätta hur det är för dig att leva med ett abdominllt aorta aneurysm (bråck på kroppspulsådern)

Intervjufrågor och exempel på följdfrågor

- När kallelsen till screening undersökning kom i brevlådan, vad var det som gjorde att du bestämde dig för att gå?
- Kan du berätta om den dagen då du fick diagnosen!
- Skulle du kunna kort berätta om den tiden från kallelsen fram till idag!
- Vad visste du om abdominellt aorta aneurysm när kallelsen kom hem i brevlådan?
- Kan du berätta vad du vet om abdominellt aorta aneurysm idag!
    - ⇒ Berätta gärna om den ärftliga betingelsen i sjukdomen
- Berätta gärna om informationen du har fått från hälso och sjukvården gällande ditt aneurysm
    - ⇒ Gav de dig några restriktioner? Vilka i så fall?
- Med tanke på den erfarenheten som du har idag. Skulle du kunna ge hälso och sjukvården några förslag till förbättring gällande information, stöd eller något annat som du ha saknat.
- Kan du berätta om den informationen som du fick med kallelsen
    - ⇒ Var där någon annan typ av information som du skulle uppskattat innan du bestämde dig för att låta dig bli undersökt?
- Berätta när du påminns om ditt aneursysm.
    - ⇒ Någon speciell situation?
    - ⇒ Hur hanterar du de situationerna? (när du använder dessa eller denna så har man det i singulär form – dessa situationer)
    - ⇒ Hur ofta på ett ungefär har du dessa tankar?
    - ⇒ Med vem delar du dessa tankar?
- Hur ser du på att träffa andra som också har aorta aneurysm, för att dela era funderingar?
- Under de åren som du har levt med vetskapen om ditt aneurysm, hur har dina tankar förändrats?
- Berätta gärna om stödet du får från hälso och sjukvården
- Skulle du kunna berätta om du har gjort några förändringar i ditt sätt att leva
    - ⇒ Något i din livsstil som du har förändrat?, Rökvanor, motion, kost?

    - ⇒ Berätta gärna vad du vet om sambandet mellan rökning och aorta aneurysm.
    - ⇒ Skulle du uppskatta att få professionell hjälp att förändra din livsstil

- o Vad uppskattar du mest med screening programmet? Vad uppskattar du minst?
- o Med den vetskapen som du har idag skulle du återigen bestämma dig för att gå och bli undersökt?

Ytterligare förslag till fördjupning av frågor

- o Kan du beskriva/förklara ytterligare
- o Kan du klargöra
- o Kan du berätta mer om…

Sammanfattningsvis

- o Du har berättat det här för mig
- o Din upplevelse av att leva med ett abdominellt aorta aneurysm är…
- o Har du något annat som du vill tillägga eller berätta?

Appendix 11: Interview guide for partners (Swedish version)

Introduktion

- Syftet med studien
- Del av ett doktorand projekt
- Intervjuerna kommer att spelas in med deltagarnas tillåtelse
- Det är frivilligt att delta och varje enskild har rätt att dra sig ur studien när som

Öppnings fråga

- Kan du berätta hur det är för dig att leva med en man som har ett screening-upptäckt abdominellt aorta aneurysm (bråck på kroppspulsådern)!
  - ⇒ Hur påverkar det dig? Varför tror du att det påverkar dig
  - ⇒ Varför påverkas du inte av det?
  - ⇒ Vad betyder det för dig…?

Intervjufrågor och probes

- När din partner fick kallelsen till screeningen, vad tänkte du då?
- Kan du berätta vad du visste om aorta aneurysm då!
- Vad vet du om aneurysm idag?
  - ⇒ Varifrån har du fått den kunskapen?
  - ⇒ Skulle du vilja veta mer? Vad skulle du vilja veta mer om?
  - ⇒ Varför vill du inte veta mer?
  - ⇒ Skulle du kunna berätta vad du vet om den ärftliga betingelsen gällande aneurysm
  - ⇒ Berätta lite om den informationen som ni har fått i samband med screening
- Kan du försöka att dra dig till minnes till dagen då din partner blev screenad för första gången och fick sin diagnos. Hur reagerade du då?
- Skulle du kunna berätta om dina tankar och reaktioner från den dagen fram till idag.
  - ⇒ Har de förändrats något? Hur i så fall?
  - ⇒ Vad är anledningen tror du till att de har förändrats?
- Finns det någon speciell situation som du tänker på aneurysmet mer än annars? När?
  - ⇒ Hur ofta har du dessa tankar?
  - ⇒ Kan du försöka förklara vad det är för tankar/känslor och hur de påverkar dig.
  - ⇒ Hur hanterar du dess reaktioner/tankar?
  - ⇒ Är det något som ni pratar om? Varför inte?
- Berätta om informationen som ni har fått gällande livstil och dess påverkan på aneurysmet.
  - ⇒ Skulle du kunna berätta lite om er livstil. (mat, motion, rökning)

        - ⇒ Hur är det, röker du eller har gjort tidigare?
        - ⇒ Skulle du kunna berätta om ni som par har gjort några livsstilsförändringar sedan ni fick reda på aneurysmet. Hur ser de förändringarna ut?
        - ⇒ Har ditt liv förändrats? Hur i så fall.
    - Berätta om den vad den största utmaningen är för dig att leva med vetskapen om din partners aneurysm.
    - Berätta hur du stöttar din partner!
    - Känner du någon annan som har ett aneurysm eller är anhörig till någon som har ett aneurysm. Vad har ni i så fall delat för erfarenheter?
    - Med den erfarenheten som du har av att leva med en man som har ett aneurysm. Vad/ hur skulle du vilja att hälso och sjukvården gjorde för att förbättra stödet/informationen/något annat för er. Vad skulle du uppskatta för stöd och när?

Ytterligare förslag till fördjupning av frågor

- Kan du beskriva/förklara ytterligare
- Kan du klargöra
- Kan du berätta mer om…

Sammanfattningsvis

- Du har berättat det här för mig
- Din upplevelse av att leva med en partner som har ett abdominellt aorta aneurysm är…
- Har du något annat som du vill tillägga eller berätta?

Appendix 12: Interview guide: Focus group interview with health care professionals working with AAA screening (Swedish version)

Intervjuguide fokusgrupp AAA screening personal

Introduktion:

- Välkomna till fokusgrupp diskussion där vi ska försöka belysa män med screening diagnostiserat AAA och deras anhörigas eventuella behov av stöd och information utifrån er kliniska erfarenhet.
- Kom ihåg att det finns inget rätt och fel på frågorna.
- Det som berättas under den här diskussionen förblir konfidentiellt.
- Du uppmanas att svara på dina kollegors kommentarer men vi försöker prata en i taget**.**
- Intervjuerna kommer att spelas in.

Öppningsfråga:

- Baserat på din erfarenhet hur uppfattar du att männen som diagnostiseras med ett AAA och deras anhöriga upplever deras situation.

  Följdfrågor:
  - Skulle ni kunna ge exempel på….
  - Vad är er uppfattning? Förändras deras upplevelser över tiden som de går på screeningen, hur i så fall och vad kan det bero?
  - *(Uppfattar ni att deras upplevelser förändras om AAA växer?)*

Intervjufrågor:

- Hur uppfattar ni att patienterna och deras anhöriga upplever informationen ni ger?

  Följdfrågor:
  - Skulle du kunna ge exempel på den informationen ni ger.
  - Hur följer ni upp den informationen?
  - Kan du berätta om informationen du ger kring sekundärprofylax. (inkl rökstopp) Anser ni att det är en del av behandlingen för de här patienterna?
  - Om ni skulle ändra något kring informationen ni ger, vad skulle det vara?
  - Om patienterna eller deras anhöriga har frågor till er, vad handlar de om?
  - Hur ser balansen ut mellan den muntliga och skriftliga informationen som ni ger?
  - Vad är det för information som ges under screening tillfället och hur skiljer den sig från informationen som ges under läkarbesöket?

- Förutom informationen ni ger patienterna och deras anhöriga berätta hur ert stöd för dem kan se ut.

  Följdfrågor:
  - Skulle ni kunna berätta mer om…
  - Har din syn på stöd för patienterna och deras anhöriga förändrats under den tiden som du har arbetat med screening?
  - Vad är det viktigaste att komma ihåg gällande det stöd som ni ger?

    - Skulle ni kunna ge exempel på något stöd eller information som ni har gett som har fått extra betydelse för patienterna eller deras anhöriga!
    - Vem har patienterna möjlighet att kontakta mellan screening undersökningarna om de har frågor eller är oroliga?
    - Med er arbetslivs erfarenhet, anser ni att det skulle finnas behov av annat stöd till patienterna och deras anhöriga och hur skulle det i så fall se ut?
    - Vad är patienterna eller deras anhöriga mest oroliga för?
    - Vad är extra bra med AAA screening programmet?

- Om ni fick möjlighet att förändra något som skulle kunna förbättra patienterna och deras anhörigas situation vad skulle det var då?

- Vad anser ni är mest utmanande för patienterna som lever med AAA och deras anhöriga?

Sammanfattning:

- Ni har berättat om att ni upplever informationen och stödet till patienterna som….
- Er uppfattning av patienternas situation är….

- Är det någon som vill tillägga något så är ni välkomna!

Appendix 13: Memos: Examples of personal reflections after interviews

September 2017

This man was so afraid and irritated. His aneurysm was 53 mm and the only thing he wanted was for the AAA to grow and become 55 mm so he could undergo an operation. He had told the health care professionals several times that he wanted an operation as soon as possible. He considered them arrogant for making him wait. Because of this, he had started to look for operations abroad.

It was hard to listen to his frustration. I really wanted to help him, especially by explaining the reason why he should continue to wait. For me, this was really frustrating. I wanted to call my colleagues at the screening clinic to let them know about his thoughts. Anyway, I realised that I while could continue to explain, the only thing he was looking forward to was his AAA becoming 55 mm.

October 2017

I was confused. This man was so afraid of an operation on his AAA because he had studied the statistics, which mention that more than 50% died during the operation. During the whole interview, he came back to this. So many that go through the operation die.

I understood that he had read about emergency operations, but I could not say anything. I understood during the interview that his aneurysm was over 50 mm and he was coming closer to the offer of undergoing an elective operation. He was afraid. I felt sorry for him and was at the same time surprised and thought: what kind of information has he gotten? Were his thoughts blocked during the consultation? He was in a horrible situation, going around and being afraid all the time—maybe because of a misunderstanding.

Afterwards, I asked when it was time for his next follow-up and encouraged him to talk to the health care professionals next time and also contact the open vascular clinic if he had concerns regarding an eventual operation.

Appendix 14: Memos: Example summary of a conducted interview

The interview took place in their kitchen while we were drinking coffee. A tidy house, just outside the city. She seemed a bit stressed, but after a while, she became more relaxed. It seemed that her husband's AAA really worried her and limited her life. She wanted to travel but was too afraid of something happening when they were away. She complained about her bad English and that maybe she could not even be able to call an ambulance. Even worse, she wondered what she would do if he died while they were away. She had really tried to help with her husband's lifestyle. But it seemed that she did it in the wrong way. She tried to encourage him to do what she liked. But she could not understand why he did not want to join her or why he was upset with her. She had so many questions and I was wondering why they don't talk with each other. At the same time, I felt sorry for her not being able to reach out to her husband. I had many thoughts regarding their relationship and if the AAA would end their marriage since she was so stressed and nervous about it. I also had a feeling that she blamed him in some way, for not staying healthy.

During the interview, she interrupted with many questions along the way and it seemed to stress her that she could not ask the questions. Therefore, I wrote them down for her, asked her to come back to them after the interview and mentioned that she should try to concentrate on the interview first.

Appendix 15: Memos: Notes during the data collection process and reflections on my interview technique

I have now conducted some interviews with both the men and their partners. It was fun to meet the participants, especially in their own homes. They have much to tell and I finally felt that I had the time to listen. However, it is a challenge not to start asking questions that the participants can only reply “Yes” or “No” to. If that is done, the conversation about that topic is over.

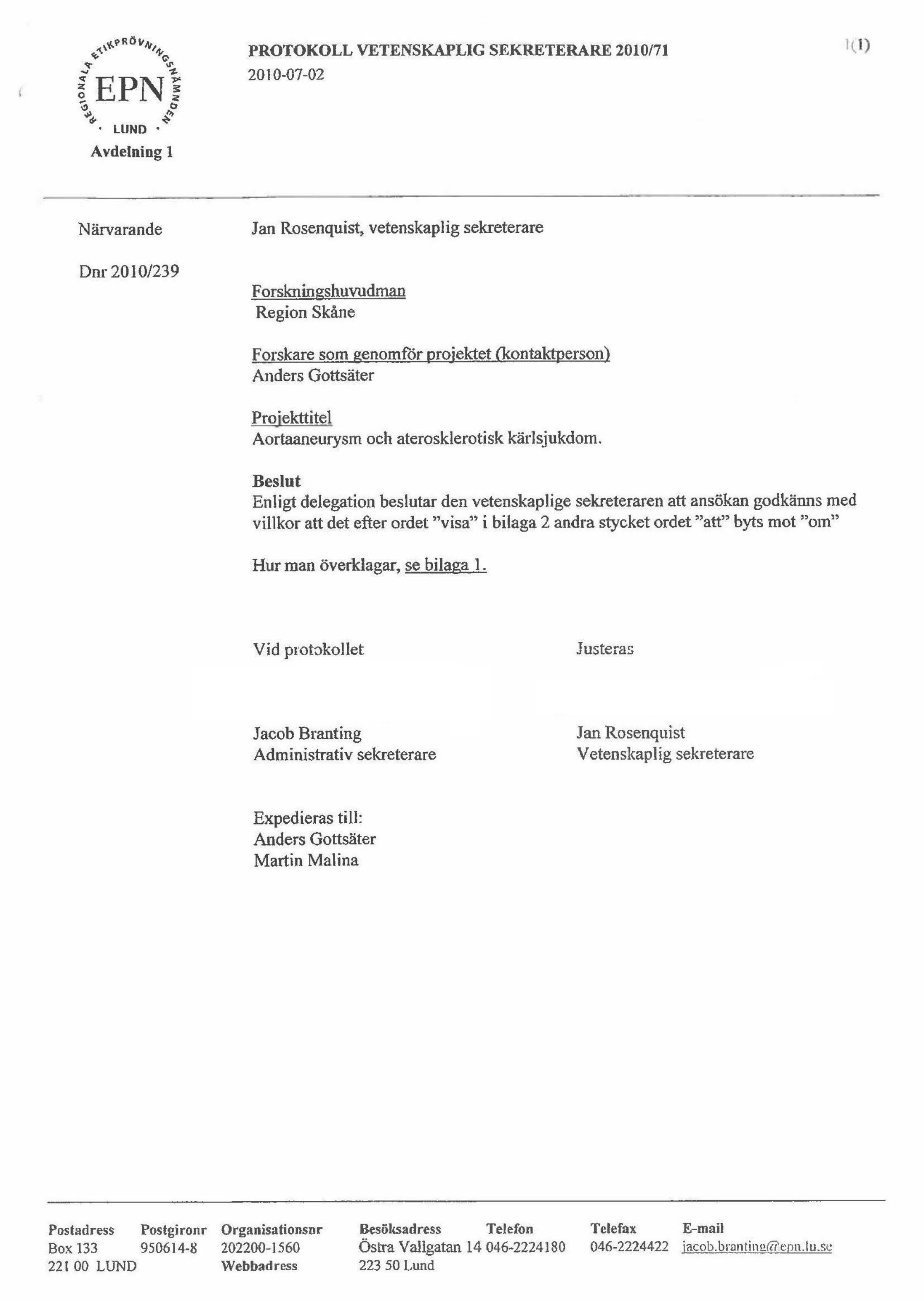
After discussions with my supervisors, they advised me to try listening more: pick up what they were saying and make notes during the interviews with short words so I can remember what they said. Furthermore, I asked the participants to give examples and explain more. “I should dig deeper into their experiences”. I felt that the coming interviews were better, although what really helped me was that we changed the opening question. It became broader: “Can you please tell me what it is like for you to live with an AAA?”

Who am I when I conduct the interviews? I wish I could say. I am Anna and I am a PhD student. Although I do feel that I am a nurse and that I act as a nurse. Sometimes, it is more or less me taking their anamneses instead of interviewing them.

After discussions, we (supervisors and me)decided that I should really present myself as a PhD student and not even mention the word nurse. When I entered the room, I would put my PhD hat on. Easy? Not really. However, I really tried to keep it in my mind and slowly I changed my mindset.

To continue, I realised that the participants I interviewed had so many questions. “What is an AAA?”, What are the reasons?”, “Can we continue to travel?”, “What are the vital signs for a rupture?”, “Who shall I call?” and so on. All of these questions were interrupted. Furthermore, it was essential for me not to leave these participants with so many questions. I know… now I am thinking like a nurse. However, what I did instead was ask them to keep their questions for the end of the interview. I summarised all the questions and normally stayed a while after the interviews to discuss the questions with them.

Appendix 16: Ethical clearance from the Central Ethical Review Board in Lund, Sweden: For interviews with men that have a screening-detected AAA



REGIONALA ETIKPRÖVNINGSNÄMNDEN
EPN
LUND
Avdelning 1

PROTOKOLL VETENSKAPLIG SEKRETERARE 2010/71
2010-07-02

1(1)

Närvarande — Jan Rosenquist, vetenskaplig sekreterare

Dnr 2010/239

Forskningshuvudman
Region Skåne

Forskare som genomför projektet (kontaktperson)
Anders Gottsäter

Projekttitel
Aortaaneurysm och aterosklerotisk kärlsjukdom.

Beslut
Enligt delegation beslutar den vetenskaplige sekreteraren att ansökan godkänns med villkor att det efter ordet "visa" i bilaga 2 andra stycket ordet "att" byts mot "om"

Hur man överklagar, se bilaga 1.

Vid protokollet

Jacob Branting
Administrativ sekreterare

Justeras

Jan Rosenquist
Vetenskaplig sekreterare

Expedieras till:
Anders Gottsäter
Martin Malina

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Box 133	950614-8	202200-1560	Östra Vallgatan 14	046-2224180	046-2224422	jacob.branting@epn.lu.se
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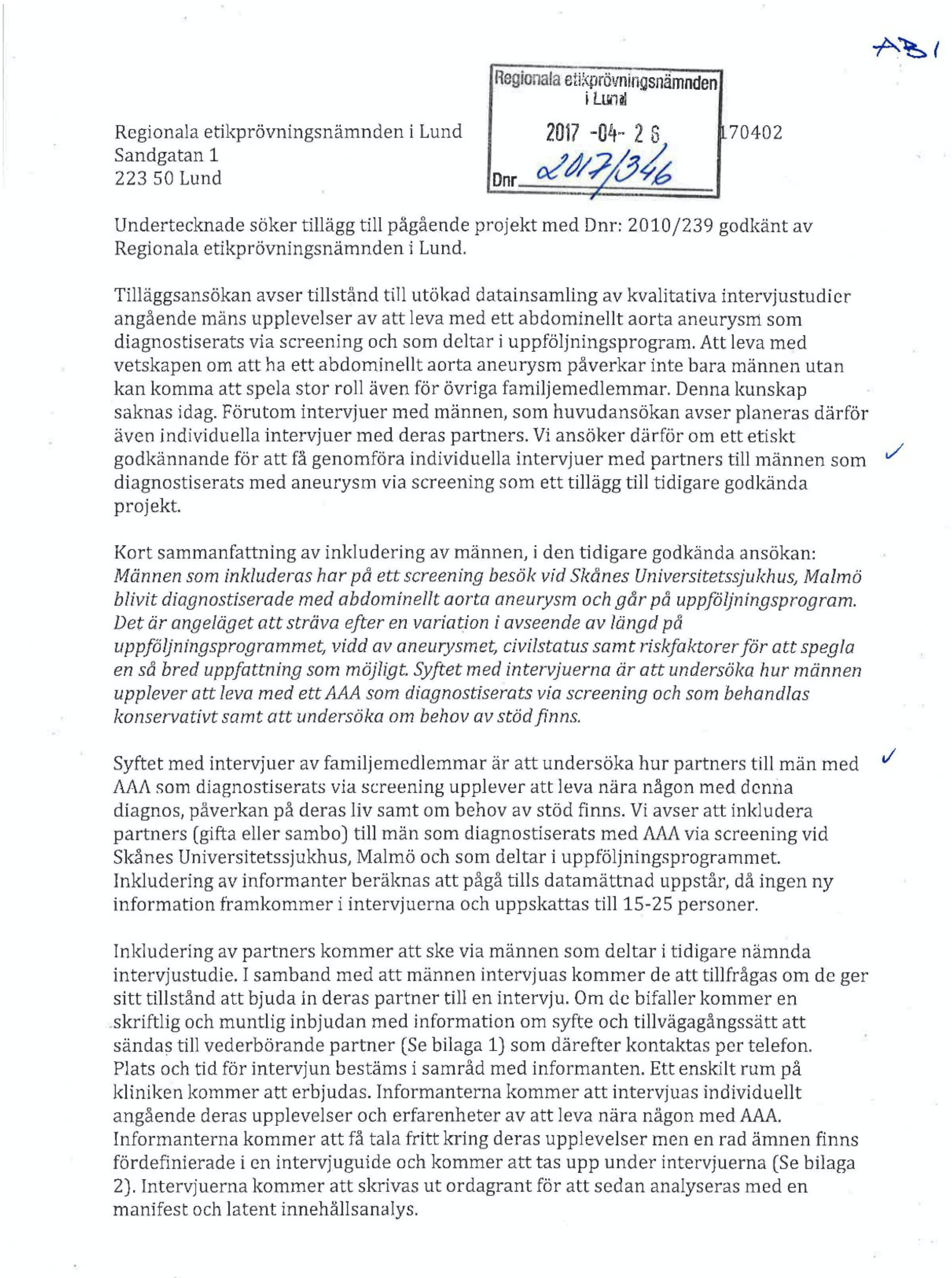
Appendix 17: Ethical Clearance from the Central Ethical Review Board in Lund, Sweden: For interviews with partners living with men that have screening-detected AAAs



AB1

Regionala etikprövningsnämnden
i Lund
2017 -04- 26
Dnr 2017/346

Regionala etikprövningsnämnden i Lund
Sandgatan 1
223 50 Lund

170402

Undertecknade söker tillägg till pågående projekt med Dnr: 2010/239 godkänt av Regionala etikprövningsnämnden i Lund.

Tilläggsansökan avser tillstånd till utökad datainsamling av kvalitativa intervjustudier angående mäns upplevelser av att leva med ett abdominellt aorta aneurysm som diagnostiserats via screening och som deltar i uppföljningsprogram. Att leva med vetskapen om att ha ett abdominellt aorta aneurysm påverkar inte bara männen utan kan komma att spela stor roll även för övriga familjemedlemmar. Denna kunskap saknas idag. Förutom intervjuer med männen, som huvudansökan avser planeras därför även individuella intervjuer med deras partners. Vi ansöker därför om ett etiskt godkännande för att få genomföra individuella intervjuer med partners till männen som diagnostiserats med aneurysm via screening som ett tillägg till tidigare godkända projekt. ✓

Kort sammanfattning av inkludering av männen, i den tidigare godkända ansökan:
Männen som inkluderas har på ett screening besök vid Skånes Universitetssjukhus, Malmö blivit diagnostiserade med abdominellt aorta aneurysm och går på uppföljningsprogram. Det är angeläget att sträva efter en variation i avseende av längd på uppföljningsprogrammet, vidd av aneurysmet, civilstatus samt riskfaktorer för att spegla en så bred uppfattning som möjligt. Syftet med intervjuerna är att undersöka hur männen upplever att leva med ett AAA som diagnostiserats via screening och som behandlas konservativt samt att undersöka om behov av stöd finns.

Syftet med intervjuer av familjemedlemmar är att undersöka hur partners till män med AAA som diagnostiserats via screening upplever att leva nära någon med denna diagnos, påverkan på deras liv samt om behov av stöd finns. Vi avser att inkludera partners (gifta eller sambo) till män som diagnostiserats med AAA via screening vid Skånes Universitetssjukhus, Malmö och som deltar i uppföljningsprogrammet. Inkludering av informanter beräknas att pågå tills datamättnad uppstår, då ingen ny information framkommer i intervjuerna och uppskattas till 15-25 personer. ✓

Inkludering av partners kommer att ske via männen som deltar i tidigare nämnda intervjustudie. I samband med att männen intervjuas kommer de att tillfrågas om de ger sitt tillstånd att bjuda in deras partner till en intervju. Om de bifaller kommer en skriftlig och muntlig inbjudan med information om syfte och tillvägagångssätt att sändas till vederbörande partner (Se bilaga 1) som därefter kontaktas per telefon. Plats och tid för intervjun bestäms i samråd med informanten. Ett enskilt rum på kliniken kommer att erbjudas. Informanterna kommer att intervjuas individuellt angående deras upplevelser och erfarenheter av att leva nära någon med AAA. Informanterna kommer att få tala fritt kring deras upplevelser men en rad ämnen finns fördefinierade i en intervjuguide och kommer att tas upp under intervjuerna (Se bilaga 2). Intervjuerna kommer att skrivas ut ordagrant för att sedan analyseras med en manifest och latent innehållsanalys.

Deltagandet är frivilligt och informanterna kan när som dra sig ur studien utan påverkan för fortsatt kontakt med vården. Skriftligt samtycke till deltagande samt till att intervjun spelas in kommer att samlas in före intervjun. Deltagandet kommer inte innebära någon risk eller obehag för informanterna.

Det är angeläget att ta reda på hur anhöriga till männen med screening diagnostiserat aneurysm upplever att leva nära någon med denna diagnos. Deras erfarenheter och upplevelser kan ligga till grund för utveckling av såväl stöd och information för både anhöriga såväl som för männen på screeningprogrammet.

Med vänlig hälsning

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BESLUT V.S 2017/106
Lund 2017-05-31
Ansökan godkänns

Njung
kaplig sekreterare
nala etikprövningsnämnden I Lund
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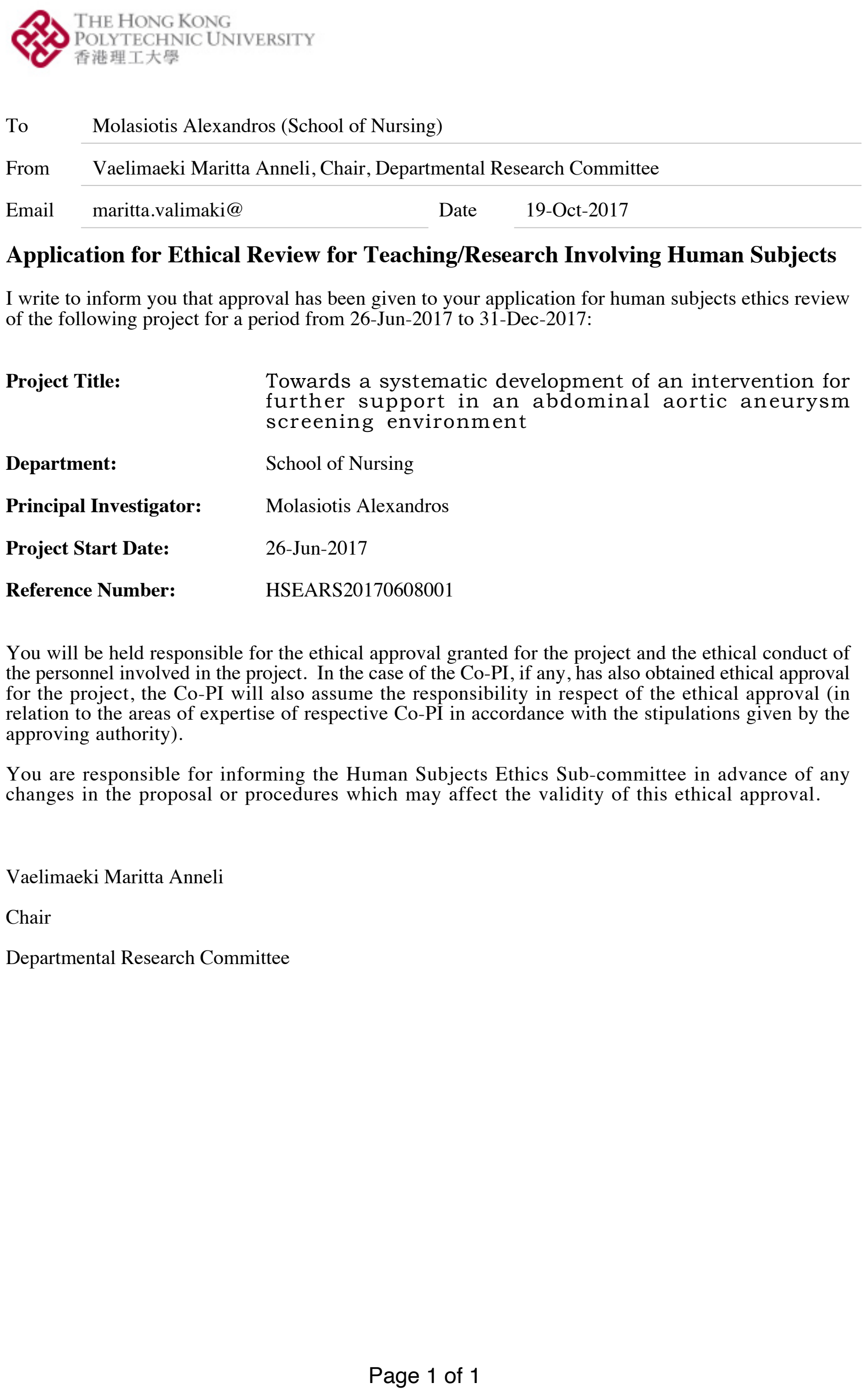
Appendix 18: Ethical Clearance for interviews with men and partners from the Hong Kong Polytechnic University



THE HONG KONG POLYTECHNIC UNIVERSITY
香港理工大學

To Molasiotis Alexandros (School of Nursing)
From Vaelimaeki Maritta Anneli, Chair, Departmental Research Committee
Email maritta.valimaki@ Date 19-Oct-2017

Application for Ethical Review for Teaching/Research Involving Human Subjects

I write to inform you that approval has been given to your application for human subjects ethics review of the following project for a period from 26-Jun-2017 to 31-Dec-2017:

Project Title:	Towards a systematic development of an intervention for further support in an abdominal aortic aneurysm screening environment
Department:	School of Nursing
Principal Investigator:	Molasiotis Alexandros
Project Start Date:	26-Jun-2017
Reference Number:	HSEARS20170608001

You will be held responsible for the ethical approval granted for the project and the ethical conduct of the personnel involved in the project. In the case of the Co-PI, if any, has also obtained ethical approval for the project, the Co-PI will also assume the responsibility in respect of the ethical approval (in relation to the areas of expertise of respective Co-PI in accordance with the stipulations given by the approving authority).

You are responsible for informing the Human Subjects Ethics Sub-committee in advance of any changes in the proposal or procedures which may affect the validity of this ethical approval.

Vaelimaeki Maritta Anneli

Chair

Departmental Research Committee

Page 1 of 1