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DEVELOPMENT, EVALUATION AND PATIENT EXPERIENCES OF EHEALTH IN THE CARE OF ABDOMINAL AORTIC ANEURYSM

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DEVELOPMENT, EVALUATION AND PATIENT EXPERIENCES OF EHEALTH IN THE CARE OF ABDOMINAL AORTIC ANEURYSM

THESIS FOR DOCTORAL DEGREE (Ph.D.)

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ABSTRACT

Abdominal aortic aneurysm (AAA) is a weakening and widening of the abdominal aorta to a diameter of 30 mm or more. It is a fairly common condition among older men, and rarely occurs in women. The condition is generally asymptomatic with a slow expansion rate over time. However, AAA rupture is associated with a high mortality and immediate surgical intervention is required. Patients with larger AAA are offered surgical repair to prevent future rupture. Diagnosis, surveillance and surgical treatment impact patients' wellbeing negatively, and previous studies have highlighted the need for adequate and timely information to prepare patients for the surgical care trajectory. However, patients' learning needs and perceptions of methods for patient education had not been clarified. Furthermore, little was known about the utilization of modern technology for learning among patients with AAA.

The overall aim of this thesis was to investigate the perceived need of learning and psychosocial support in patients with AAA, and evaluate methods to accommodate these needs in a clinical setting.

The thesis comprises four scientific papers. **Studies I and IV** are qualitative interview studies, **study II** uses mixed methodology and **study III** is a randomized, controlled trial. **Study I** aimed to describe AAA patients' perceived learning needs and explore their experience of different methods for patient education. Our results show that patients' learning needs are not met by the health care staff, and that they therefore refer to other sources for information. Participants warranted continuous contact with a trusted person for follow-up and support.

In **study II**, an eHealth tool was developed and validated for patients with AAA using a participatory design process. Patients, eHealth developers and health care staff were engaged in the design process, and readability analyses were performed. The final version of the eHealth tool was deemed accurate and relevant, and the language was perceived as understandable. However, the readability analyses produced readability scores exceeding the average literacy levels of older adults.

Study III was a randomized, controlled trial with 120 patients scheduled for AAA repair. In the study, the eHealth tool and tailored psychosocial support was evaluated as an adjunct to standard care. The intervention was evaluated by repeated measurements with validated instruments (HADS and SF-12) to assess symptoms of anxiety and depression, and health-related quality of life. In the intervention group, 30 participants (50%) used the eHealth tool. App users were younger and had higher educational level than non-users. No significant difference was noted in anxiety mean score analyses between the whole intervention group and the control group. Those who utilized the complete intervention had markedly lower anxiety mean scores at the postoperative follow-up compared to the control group. Patients with low educational level had sustained high anxiety levels postoperatively.

In **study IV**, a qualitative evaluation of the intervention by individual, in-depth interviews with 12 participants from the intervention group in **study III** was performed. When offered the eHealth tool, participants familiarity with modern technology was influential in their decision to engage in the tool. Those who were unfamiliar with this technology refrained from using the eHealth tool. Furthermore, their mental state at baseline, one week prior to surgery, hindered them to partake in the intervention. The implication and relevance of psychosocial support was not evident to the participants during the perioperative phase but could be understood in retrospect. Adjustment of information to the patient's mental state and learning needs was believed to quench anxiety.

In summary, this thesis provides insight into patients' perspective on learning and psychosocial support in the AAA care trajectory. It also elucidates the feasibility and effects of an eHealth intervention to decrease anxiety. The studies also shed light on vulnerable groups which risk negative consequences of the digitalization of healthcare, such as those with low educational level and older patients. For successful implementation of eHealth services, future research and quality improvement initiatives should include targeted initiatives to strengthen these groups.

POPULÄRVETENSKAPLIG SAMMANFATTNING

Stora kroppspulsådern (latin: aorta) är kroppens största blodkärl och transporterar syrerikt blod från hjärtat ut till kroppens alla organ och vävnader. Kroppspulsåderbräck, även kallat bukaortaaneurysm, är en sjuklig vidgning av kroppspulsådern i buken. Orsakerna bakom sjukdomen är till viss del okända men sjukdomen är överrepresenterad bland äldre män och rökare. Bukaortaaneurysm växer långsamt och opereras inte förrän risken för ruptur (bristning) överväger risken med behandlingen, vanligen när aneurysmdiametern är 5,5 cm. Sjukdomen ger i regel inga symtom, sjukdomsbeskedet kan därför vara chockartat och behovet av kirurgisk behandling svårgreppbart för patienter och anhöriga. Bukaortaaneurysm opereras med öppen bukkirurgi eller endovaskulär (röntgenledd) teknik. De två operationsmetoderna skiljer sig i vårdförlopp och komplikationsfrekvens. Av de båda operationstyperna så har öppen kirurgisk behandling störst inverkan på den fysiska hälsan i det korta perspektivet, men båda operationstyperna kan ha en negativ inverkan på hälsorelaterad livskvalitet.

Enligt svensk lagstiftning ska patienter få tillräcklig kunskap för att möjliggöra delaktighet i vård och behandling. Forskning har dock visat att det idag saknas enhetlig och lättillgänglig information för patienter och anhöriga. Studier har också visat att befintligt informationsmaterial har ett alltför avancerat språk som inte motsvarar läskunnigheten hos patienter och anhöriga. Hos andra patientgrupper har man även sett att information som förmedlas vid fel tidpunkt eller som inte anpassas till patientens behov kan få negativa konsekvenser för patienters mående.

I delarbete I utforskades patienters behov av lärande och stöd. Resultaten tyder på att vården inte tillgodoser de lärandebehov som finns hos patienter med bukaortaaneurysm, samt att patienter upplever bristande stöd från vården. De inhämtar därför information från andra källor, såsom internet eller genom samtal med vänner och anhöriga. Patienterna värdesätter kontinuerlig kontakt med en namngiven person inom vården för uppföljning och stöd.

Inom ramen för det andra delarbetet utvecklades ett eHälsoverktyg i form av en mobilapplikation. I designprocessen involverades patienter och vårdpersonal, eHälsoverktyget utvärderades även avseende läsbarhet. Texter och illustrationer i den slutliga versionen av appen bedömdes vara på en god språklig nivå, och i omfattning motsvara den information som vårdpersonal och patienter önskat. Analysen av läsbarhet antydde dock att språket var på en alltför hög nivå, trots upprepade revideringar.

I det tredje delarbetet blev patienter som planerades för operation av bukaortaaneurysm slumpvis delade i en interventionsgrupp och en kontrollgrupp. Kontrollgruppen fick vanlig standardinformation och uppföljning. Interventionsgruppen fick tillgång till eHälsoverktyget i kombination med strukturerat, personcentrerat psykosocialt stöd. Hälften av dem som erbjöds eHälsoverktyget använde det. De som använde mobilapplikationen var yngre och hade högre utbildningsnivå än icke-användarna. De som tog del av hela interventionen med eHälsoverktyg och psykosocialt stöd hade betydligt lägre ångestnivåer efter operationen än

kontrollgruppen. Vid uppföljningen efter operationen noterades kvarstående höga ångestnivåer hos patienter med låg utbildningsnivå.

Den fjärde och avslutande studien var en utvärdering av interventionsstudien, där 12 deltagare ur interventionsgruppen deltog i enskilda intervjuer för att ge en fördjupad bild av upplevelsen av att delta i denna typ av intervention. Deltagarnas vana av modern teknik var vägledande för deras beslut att använda eHälsoverktyget. De beskrev också att de upprätthöll sitt ordinarie beteende vad gäller informationssökning, samt att de inte alltid insåg behovet av psykosocialt stöd eller information förrän i efterhand. Det psykosociala stödet gav en kontinuitet och trygghet som värderades högt. Anpassning av information till patientens informationsbehov och psykiska mående var avgörande för att förebygga ångest.

Tillsammans bidrar projekten till en ökad förståelse för patienters upplevelse av lärande och stöd i samband med vård och behandling av bukaortaaneurysm. Projektet klargör också relevansen och effekten av ett validerat eHälsoverktyg för denna patientgrupp. De belyser också sårbara grupper som kan drabbas negativt av digitaliseringen av sjukvården. Framtida forskning bör innefatta riktade insatser för att inkludera äldre och lågutbildade.

LIST OF SCIENTIFIC PAPERS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals as indicated below.

I. Perceived learning needs of patients with abdominal aortic aneurysm.

Olga Nilsson, Rebecka Hultgren, Anna Letterstål

Journal of Vascular Nursing. 2017;35(1):4-11

II. eHealth tool for patients with abdominal aortic aneurysm: development and initial evaluation.

Olga Nilsson, Rebecka Hultgren, Anna Letterstål

Scandinavian Journal of Caring Sciences. 2020 Jun;34(2):348-356.

III. The effect of an eHealth intervention on anxiety in patients undergoing abdominal aortic aneurysm surgery: a randomized, controlled trial.

Olga Nilsson, Malin Stenman, Anna Letterstål, Rebecka Hultgren

Manuscript submitted

IV. Experiences of participating in an eHealth intervention for patients with abdominal aortic aneurysm.

Olga Nilsson, Rebecka Hultgren, Anna Letterstål

Manuscript submitted

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LIST OF ABBREVIATIONS

AAA	Abdominal aortic aneurysm
COPD	Chronic obstructive pulmonary disease
DHT	Digital health technology
eHealth	Electronic health
EVAR	Endovascular aortic repair
FGI	Focus Group Interview
FKGL	Flesch-Kincaid Grade Level
FRES	Flesch Reading Ease Score
HADS	Hospital Anxiety and Depression Scale
HRQoL	Health-related quality of life
MCS	Mental component summary
OR	Open repair
PCC	Person-centered care
PCS	Physical component summary
PD	Participatory design
PROM	Patient reported outcome measure
RCT	Randomized, controlled trial
RN	Registered nurse
SF-12	12-item Short form health survey

1 INTRODUCTION AND FOREWORD

This doctoral thesis focuses on the usefulness and relevance of eHealth in the care of patients with abdominal aortic aneurysm (AAA). The idea of developing and testing an electronic information material at the Department of Vascular Surgery first arose in 2011. Anna Letterstål and Rebecka Hultgren, who both had devoted their research to patients with AAA, were determined to improve the information provided to patients and next of kin. In Anna Letterståls thesis, the need for structured information and improved dialogue between patients and health care staff had been identified and we were eager to investigate this further.

My first encounter with in-patient vascular nursing care was during my first employment as a registered nurse at Karolinska University Hospital in the spring of 2008. Caring for patients and their loved ones in their most trying times was a very rewarding experience but early on, it was clear to me that AAA patients were not fully aware of the severity of the surgery they were facing. Often when we would transfer patients from the ICU back to the vascular surgery ward postoperatively, they seemed terrified and completely unprepared for the postoperative care that lay ahead. Their recollection of the information they had received prior to surgery also varied largely. Irrespective of the amount of time and effort being put into informing patients about a planned procedure, they sometimes had no recollection of their preoperative out-patient visit at all. It sometimes seemed like they were completely blocked to the information we as healthcare staff were trying to provide.

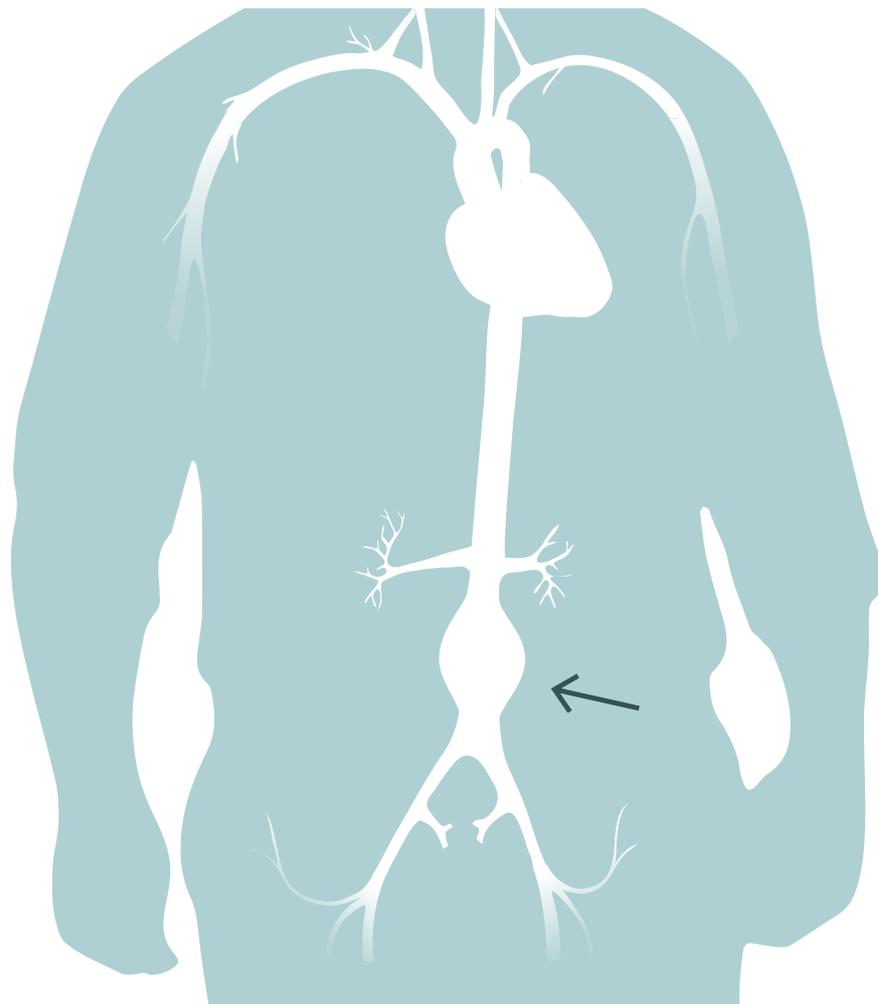
At that time, I had no experience or particular interest in clinical research but I was baffled by the apparent discrepancy in what we as health care staff believed that we conveyed, and what patients perceived. Through this thesis, we hope to shed some light on the processes that foster and hinder patients' learning, and the ways in which eHealth can prove useful in this context.

2 BACKGROUND

2.1 ABDOMINAL AORTIC ANEURYSM

2.1.1 Definition and anatomy

The aorta is the body's largest blood vessel, transporting oxygenated blood from the left ventricle through the thoracic cavity to the brain, abdominal organs and peripheral tissue. The abdominal aorta is delimited cranially by the diaphragm, and is commonly divided into the suprarenal (above the renal arteries) and infrarenal (below the renal arteries) segments. The bifurcation to the iliac arteries marks the distal end of the abdominal aorta. An aneurysm is a weakening of a blood vessel wall, which causes the vessel to bulge. Arterial aneurysms can develop in any artery in the body, but is most commonly found in the abdominal aorta. The exact pathology is not yet fully understood but degradation of collagen and elastin in the aortic media as well as apoptosis of smooth muscle cells in the aortic wall are both associated with aneurysm formation in the abdominal aorta. If the diameter of the aorta exceeds 30 mm in men, or 27 mm in women, it is defined as an aortic aneurysm. (1) This thesis will exclusively pertain to patients with abdominal aortic aneurysm (AAA), located in the infrarenal aorta.



2.1.2 Epidemiology and risk factors

AAA is a fairly common condition in the older population. In the 20th century, there was an increasing interest in the disease and large cohort studies were conducted to increase the understanding of the epidemiology and natural course of the disease. (2) These studies reported on a prevalence of 4-7.6 % among men aged 64 or higher. (3, 4) Currently, the prevalence seems to be decreasing and national population-based screening programs estimate that no more than 1.5 % of Swedish 65-year-old men suffer from the condition. (5) The condition is rare among women and the prevalence is estimated to around 0.5 % among 70-year olds. (6)

The pathophysiology of aneurysm formation remains largely unknown and the exact aetiology is yet to be determined. However, certain prominent risk factors have been associated with AAA. Among these smoking, male sex, advanced age and concomitant cardiovascular disease show the strongest correlation to AAA development. (7-9) There is also a hereditary component, where first degree relatives of patients with AAA have an increased risk of developing the disease. (10, 11) Long-term smokers have an up to eight-fold risk of developing an AAA compared to non-smokers. (12, 13) The risk of developing AAA increases with age in both men and women, but the condition is much more common in men than women with a 4-6:1 ratio. (2, 6, 14) As the aneurysm gradually increases in diameter, the risk of rupture becomes more prominent. (2) Aneurysm rupture is life threatening, causing massive internal bleeding and only 20 % survive. (15-17)

2.1.3 Diagnosis

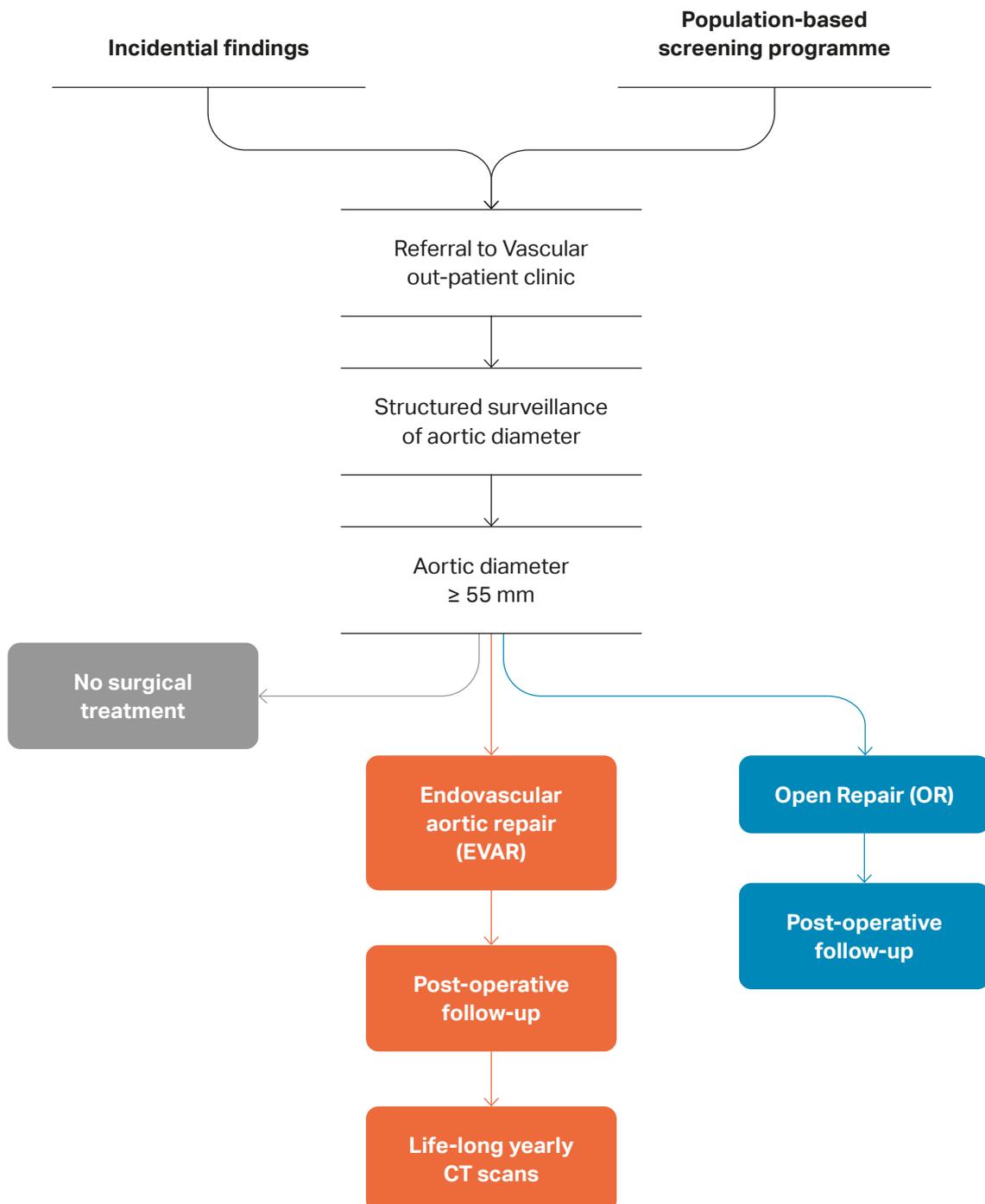
Typically, AAA is an asymptomatic condition and it can therefore go undetected for a long time. Diagnostic imaging with ultrasound or x-ray should always be performed at the suspicion of an AAA. Commonly, AAA is found en-passant in routine scans for other diagnoses or through screening. International guidelines recommend screening for early detection of AAA and prevention of rupture by surgical treatment. (1, 18) The condition is rare among women and the prevalence increases with age. Population-based screening is therefore currently provided to 65-year old men in Sweden and the UK, while several European countries have a pending start-up of screening programs. (14, 19, 20) Screening is currently not performed in first-degree relatives. Ultrasound is a fast, non-invasive diagnostic method which has proven cost-effective, it is therefore the method chosen for population-based screening programs. (21)

2.1.4 Management of patients with abdominal aortic aneurysm

Most AAAs are small upon diagnosis. AAAs grow slowly, and most patients are never apted for surgical treatment. (22, 23) As the aneurysm grows, the risk of rupture increases and the surveillance intervals are therefore more frequent. (18) The patient is monitored with an

ultrasound surveillance schedule based on the last maximum diameter of the AAA and concomitant risk factors. (24-27) The recommendations for surgical treatment are currently set at a diameter of 55 millimeters, and women are evaluated at 50-52 millimeters. (1, 18) Aside from the diameter, several medical and psychological factors can affect the decision to offer, postpone or abstain surgical treatment. (2) The process of diagnosis, monitoring and surgical treatment is outlined in Figure 1.

Figure 1. Diagnosis, management and surgical treatment of abdominal aortic aneurysm.



2.1.5 Surgical treatment and outcome

There are currently two available surgical techniques to treat AAAs; open repair (OR) and endovascular aortic repair (EVAR). The choice of surgical treatment method is based on aneurysm morphology, comorbidity, surgical risk profile and the patient's preferences. OR is performed under general anesthesia. Through a midline laparotomy, the aneurysmatic aorta is replaced with a vascular prosthesis, a robust synthetic graft material which is sewn into the aorta. EVAR was first performed by Ukrainian surgeon Nicholas Volodos in 1987, but was generally acknowledged through a later publication by Juan Carlos Parodi in 1991. (28) EVAR offers a minimally invasive alternative where a stent graft is inserted through a transfemoral approach using perioperative imaging. The procedure is typically performed under local anesthesia.

Average length of stay for patients having undergone EVAR is four days, as compared to eleven days for those treated with OR. (29) In the early postoperative phase, roughly 20 % of those treated with OR experience some form of complication, most often cardiac or respiratory. (30) Early complications following endovascular procedures are usually less severe, such as local bleeding complications from the access arteries in the groins. However, with time, an endoleak can develop. In an endoleak, blood circulates outside the stent graft and the aneurysm may increase in size. If left unmonitored and untreated, an endoleak may cause a late rupture after surgical treatment. To prevent this, patients undergoing EVAR are bound to life-long annual CT scans. Early postoperative mortality is higher in patients treated with OR than those treated with EVAR, but long-term complication and survival rates are comparable. (30-32) Elective surgical treatment with OR is however a safe procedure with very low mortality compared to those treated for an acute rupture. (1, 31, 32) AAA rupture is a life-threatening condition, without surgical treatment all patients die within hours or days. (2) Even among the patients that are surgically treated with OR or EVAR, AAA rupture is still associated with a very high mortality. (33)

2.1.6 Comorbidity and outcome

Persons developing AAA have a higher prevalence of cardiovascular disease, chronic obstructive pulmonary disease and hypertension. (7) Thereby, they have an increased disease burden as compared to the age-matched population. This discrepancy persists after surgical treatment, where patients with AAA have an increased risk of cardiac and cerebrovascular events following surgical treatment of their AAA. (7, 27, 34) When a patient is referred to the vascular surgery out-patient clinic, an assessment of the patient's general risk, such as cardiovascular diseases is made, and adequate secondary prevention initiated accordingly, often in collaboration with the general practitioner. (1) To prevent future cardiovascular events, pharmacological treatment (acetylic salicylic acid and a lipid lowering agent), smoking cessation, and life style recommendations should be provided. (35) Through

population-based screening programs, early detection of AAA and subsequent secondary prevention can be offered to this group prior to onset of manifest cardiovascular disease. (36)

2.2 THEORETICAL AND METHODOLOGICAL FRAMEWORK

2.2.1 Learning

The concept of learning is indeed contextual. Learning can be defined as “the process in a living organism which leads to a permanent change in capacity and which is not solely a consequence of biological maturity or aging”. (37) Historically, three major learning perspectives have been influential: behaviorism, cognitivism, and constructivism. According to the behavioristic perspective, knowledge is transferred from one individual to another irrespective of prior knowledge or cultural aspects. (38) The cognitive perspective, cognitivism, acknowledges the learning person’s experience and preconceptions, taking interest in the thought processes that originate learning. The learning person is considered an active partaker rather than a passive receiver of knowledge. Learning builds on previous knowledge and experience, as opposed to the behavioristic notion where information is merely registered by the recipient. (38) The constructivist perspective emphasizes the social aspects of learning, where context, interest, attitude, and personal experience impact the learning process. (39) In modern learning theory, learning is understood as an active process where the learner’s assessment of the meaningfulness and usefulness will affect the learning outcome. The learner is an active participant in the learning process and learning stems from motivation and commitment. (37)

2.2.1.1 Learning in a healthcare context

Historically, the main goal of patient education has been to impel patients to comply with prescribed medications and lifestyle changes. The term patient education in that sense refers to an activity where healthcare staff provides a patient with the information that they find appropriate for legal or practical reasons. Modern patient education is instead considered a tool to impact patients’ behaviors and attain deeper knowledge or changes in attitudes and skills necessary to maintain or improve their health. (40) Prior to a patient education intervention, the patient’s needs should be assessed. Thereafter, the patient and healthcare staff can jointly formulate individual goals. (40) Several theoretical models can be applied to adult learners in a healthcare setting, among which “adult learning theory” is the most influential. Adult learning theory, also known as andragogy, was first described by German educator Alexander Kapp in 1833 and further developed by Malcolm Knowles. (41) In andragogy, adult learners are believed to be self-directed, autonomous and goal oriented. Learning stems from and builds on previous knowledge and experience. A nonhierarchical relationship between teacher and learner is assumed to facilitate the learning process, and the teacher functions mainly as a facilitator for learning. (37) Through the years, social cognitive learning theory and self-efficacy, it’s inherent construct, have been used increasingly in the

design and implementation of patient education initiatives by the use of person-centered care (PCC). (42)

2.2.1.2 Learning as a prerequisite for participation

In recent years, patient education has grown as a research field. (38) Patient education is a key issue for patient advocacy organizations as a means to increase patients' self-care and self-efficacy in the health care context. Activities to increase patients' knowledge and participation in care have been shown to increase satisfaction with care and decrease complications during hospital stay. (43) The patient's right to information and participation in the care process is also protected by the Patients' act (2014:821), which determines that where possible, any care should be planned and carried out in consultation with the patient, and that information should be individualized. Different communication strategies have been shown to affect patients' experience of participation in decision making. (44-46) Pictures and interactive designs have also been shown to facilitate learning which in turn enables patient participation. (47, 48) The relationship between patients' knowledge and participation in care is well established and has been linked to decreased risk of complications and enhanced recovery after colorectal and cardiac surgery. (47, 49, 50) These types of education interventions have also proven effective from a health economic perspective, with better health outcomes and maintained HRQoL compared to patients receiving standard of care. (51, 52)

2.2.2 Tailoring information to patients' learning needs

2.2.2.1 Learning needs

A basic tenet to developing and providing information is the understanding of patients' learning needs, a concept which has been found to be poorly developed and theorized. (53) The term learning needs is often used without being defined and used interchangeably with related terms such as information needs and educational needs. (54, 55) Throughout this thesis, the term learning needs is used to describe patients' need of learning to understand and cope with their disease and the surgical treatment. To identify and understand specific learning needs, it is vital to understand their antecedents. The need for learning can stem from different stimuli, such as life-changing events or illnesses. (54) In these cases, information seeking behavior can be understood as a problem-focused coping mechanism. (55) Problem-focused coping, first described by Lazarus and Folkman, identifies information seeking as the most frequent method used to cope with a stressful event about which information is limited. (56) In this view, patients' information seeking behavior constitutes the core of their learning needs. (54)

2.2.2.2 Identifying patients' learning needs

During clinical consultations, health care staff often make assumptions regarding the learning needs of patients and next of kin, and tailor verbal information accordingly. Albeit, studies show that patients often experience themselves as inadequately informed. (57) Reasons are multiple, and may refer to the inability of health care staff to adequately identify the learning needs of patients, as well as an assumption that too much information may cause harm and anxiety. (57) On the other hand, patients sometimes find it difficult to estimate and express their need for information. (55) The learning needs of a specific cohort of patients can also vary depending on different factors such as gender and age. (55) In interventions targeting patients' learning needs, the selection of appropriate outcome variables is therefore vital to determine the potential effects. Common outcomes in intervention studies of learning needs are question asking, patient participation, anxiety, knowledge and consultation length. (57) In addition, there are numerous instruments aiming to capture patients' learning needs, with varying results regarding their ability to adequately elicit patients' learning needs. (58)

2.2.2.3 Learning in the context of abdominal aortic aneurysm

As AAA is commonly found incidentally or through screening programs, the notion of having this potentially lethal condition can be sudden and difficult to grasp. To minimize the negative psychological consequences of the diagnosis, it is crucial that patients and next of kin receive individualized, pertinent information about the natural course of the disease as well as the different surgical treatment techniques. The use of internet for information seeking has increased markedly in recent years, in particular in the elderly. (59) It is therefore of great importance that available web-based information is accurate and understandable to patients and next of kin. Online information about AAA has been found to be inadequate and inaccurate but available web-based information sources are not constant and such evaluations are quickly outdated. (60-62) No such evaluation has been published regarding available sources of online information targeting Swedish patients and next of kin.

In Sweden, there has historically been large discrepancies in the amount and type of information provided to patients and next of kin at different vascular surgery centers. The Swedish Society of Vascular Surgery (SSVS) and the Swedish Society of Vascular Nursing (SSVN) have therefore jointly developed patient information material for the most common conditions treated at vascular surgery departments around Sweden, as an initiative to harmonize the information provided to patients and next of kin. In addition, the Swedish Heart-Lung Foundation has published an extensive brochure about aortic disease which is also available online. (63) In addition to written information, patients are provided with oral information by vascular surgeons and nurses prior to surgical treatment. In a study by Berman and colleagues, information provided by vascular surgeons regarding the surgical treatment of AAA and the risks associated with the different treatment options was skewed by the surgeons' personal experience, surgical preference and center experience. (64) For health care

staff, providing individualized, adequate information requires acknowledging and challenging one's preconceptions and own preferences for information. (65)

Given that a patient education material is valid and relevant, it can strengthen the patient in relation to health care staff. A well-informed patient is more inclined to actively participate in decisions and activities pertaining to their care. (66) However, well-informed patients and next of kin can pose a challenge to health care staff, as it may provoke the traditional hierarchy of the health care system where patients are merely viewed as passive receivers of information. (59) Informing AAA patients of the risks associated with the disease and surgical treatment is a delicate task, requiring that patients' individual learning needs are acknowledged. (67, 68) The subject of surgical risks and complications may be particularly difficult to tailor and although it may cause anxiety, it is an inevitable part of the preoperative information package. Online information sources about AAA are known to report inadequate risk information, which may render patients unprepared for the risk information conveyed during clinical consultations. (69)

2.2.2.4 Health literacy

Health literacy is defined as the degree to which an individual has the capacity to obtain, process and understand basic health information needed to make appropriate health decisions. (70) Health literacy can be attributed to factors such as reading and numeracy skills but to some extent also relates to educational level and socioeconomic position. (71) A challenge when developing educational material regarding AAA is maintaining a language level which corresponds to the reading ability of the target group, while safeguarding that essential information is maintained and that it corresponds to the needs of the patients. If oral or written information is provided in a language which exceeds the level of the patient or next of kin, it obstructs their ability to learn and utilize information. (72) In patients with arterial vascular disease, of which AAA is a subset, 76,7 % have been found to have inadequate health literacy. (73) In an assessment of the readability and understandability of available online information about AAA, none of the websites included in the analysis provided information at a level appropriate for patient education materials. (61) Just as individual adjustment of information to patients' health literacy is a prerequisite for participation in care, failure to do so has been linked to adverse health outcomes. (74) In recent years, the term eHealth literacy has been introduced to provide insights into how health literacy is impacted by the shift to electronic health services. (75) In this context, eHealth literacy comprises "a set of skills and knowledge that are essential for productive interactions with technology-based health tools". (75) Individuals with low health literacy skills have larger difficulties in utilizing and interacting with eHealth, which may amplify the gap in accessibility and utilization of health services among certain groups in society. (76, 77)

2.2.3 Developing eHealth for patients

In recent years, mobile technology has been used increasingly to enhance the efficacy and efficiency of healthcare services. These technological advancements have been fueled by the rising burden of chronic diseases in the aging population, and the shifting focus from health systems to person-centric models. (78) WHO defines eHealth as “the use of information and communications technology in support of health and health-related fields”. (79, 80) eHealth was historically limited to the use of computers, but now encompasses various methods to deliver technological solutions or products. (79) eHealth is a broad term, relating to both patient administration systems, communication systems, digital health technology and telemedicine. mHealth is more specific and generally used to describe the transfer of health information, such as logging and monitoring a chronic condition, or accessing electronic health records. (80)

Despite the increasing body of evidence supporting the relevance and usefulness of eHealth in the management of chronic conditions, concerns relating to data security, technology or eHealth literacy, and potential negative effects have been raised. (79) In a scoping review of current practices for developing and evaluating mHealth technologies, the perceived value and ease-of-use by the end user was identified as a critical factor to successful adoption of eHealth solutions. (81) End-user engagement in the early design and development was described as crucial, and user-centered, collaborative, interdisciplinary approach to enhance the acceptability and usability of mHealth was warranted. (81) In spite of the reported benefits of user involvement in the design process, issues of *how*, *when* and *where* to engage users is subject of debate. (82)

2.2.3.1 Research methodology in eHealth development

The paradigm shift in health care services, moving from a health care centric to a patient-centric approach has brought about an increased awareness of user involvement in the design of health technology. (83) Historically, the notion of involving participants in the research process stems from the field of social science. Action research is a research method developed in the 1940s, first described by Kurt Lewin. In the 1970s, action research was used to evaluate the introduction of information technology in workplace environments. It is specifically suitable to identify and describe changes in situations or processes, and is characterized by the collaboration between researcher and participants, working closely together. With the emergence of action research, the relationship and interaction between researcher and participant was lifted and the knowledge and contributions of participants were acknowledged. One significant feature of action research is the cyclical process of action and reflection, and a systematic approach to data collection and analysis. As in other forms of educational research, the research question determined the methods for data collection, which can be both qualitative and quantitative. (84) Advancements in modern technology have spawned the theoretical and methodological plethora of educational

research, and action research has evolved in several different directions, one being participatory design (PD). (84) Action research and participatory design entail similar conceptualizations of participant involvement, and the critical task of establishing trust between researcher and participant. While action research is suitable for immersive, explorative research, participatory design is often utilized when a targeted design goal or outcome has been identified. It is therefore widely used in the development processes of health technology targeting persons with chronic conditions, where the context and goal is known. (85)

2.2.3.2 Participatory design

Participatory design (PD) is a methodology which promotes the participation of users in the design process of technological solutions. PD has its theoretical and methodological groundings in constructivism, aiming to understand the implicit or tacit knowledge of users. (86) In this viewing, users are regarded “experts by experience”, holding knowledge which is vital to the design process. (86) Through the utilization of PD methodology, developers strive to design technologies that align with the needs of the users. (87) PD involves four phases: a needs assessment of potential users, generating of ideas and prototypes, testing and developing prototypes and assessment of the effectiveness of the product in a real-life setting. (88) This approach aims to enable end-users to make use of the end-product in an intuitive and efficient way. (85)

In participatory design, the degree of user involvement can vary depending on factors such as the complexity of the system being developed and the context in which it is intended to be implemented. (82) In contrast to user-centered design and co-operative design where potential end-users function as consultants in the design process, participatory design engages end-users as co-creators and active participants in design ideas and decision making. In user-centered design, user input into design is acknowledged, their preferences and needs are investigated, and cyclic iterations are used in the design process. Co-operative design entails users and developers/designers working together to come up with designs and modifications. In this approach, the use of prototyping and simulations spurs users to explore and experience the technology. In user-driven innovation, one key challenge is creating space for users to innovate and transform their ideas into products or systems. (82)

2.2.3.3 Participatory design in eHealth targeting older adults

In the design of eHealth products targeting older adults, the engagement of potential end-users is essential. PD can help to avoid negative age-related stereotypes such as the notion that older adults are less prone or capable to engage in eHealth. (87) The use of PD approaches in eHealth design has been identified as a key issue to successful implementation, where prospective clinical trials to evaluate the applicability of eHealth is warranted. (89)

Nevertheless, the adoption of PD in the design of eHealth solutions targeting older patients faces several challenges. Older people are a heterogeneous group with diverse life situations, using and interacting with modern technology in diverse ways. (90) As eHealth may conduce to digital inequalities in underprivileged groups, this risk needs to be considered early in the design process.

Following a systematic review of involving older users in technology design, Fischer and colleagues suggest an analytical framework. (91) In this framework, the involvement of older users is outlined as a process where purposes, nature and consequences are described. Three outcomes of user involvement are identified; learning, adjusted design and sense of participation. Learning in this context refers to researchers' or developers' increased understanding and awareness of user needs and prerequisites. In some cases it can also result in mutual learning, where designers learn about the wishes of older adults, while older individuals gain increased technological competence. (91) Feedback and insights from older adults also generate adjusted design, either through revised infrastructure and prototypes or through altered or expanded outcomes by the increased understanding of end-users' perspective. The third consequence of user involvement is an increased sense of participation, where older adults are encouraged and empowered to engage in technology use. (91) However, the level of involvement varies greatly in eHealth initiatives using PD. User involvement for legitimization purposes may be counterproductive. (87) Appropriate methods and instruments are of vital importance for older users to actively influence the outcome of a design process. (87)

2.2.3.4 eHealth in the older population

When designing and evaluating education material, special attention should be placed on the variables which may affect the use and experience of the material, such as age, sex, educational level and comorbidity. (50, 92) The use of internet and modern technical devices is increasing in the general population, with the largest increase seen in the elderly. (46) Although internet usage decreases with age, more than 50% of citizens above 76 years of age use the internet. (93) Even so, a recent study of patients' information sources when facing AAA repair showed that only 10% listed the internet as their main source of information regarding their surgical treatment. (94) Older persons with access to a computer still experience a hesitancy towards using this technology to seek information. (77) Some studies suggest that older women are particularly skeptical to the use of modern technology, this may warrant targeted efforts to safeguard that this group is not excluded as technology advances and certain services move from analogue to digital solutions. (92)

2.2.4 Psychosocial support

Psychosocial support is defined as initiatives to support ongoing psychological or social problems which may have direct or indirect effect on a person's health. (95) Psychosocial

care is a key component of all nurses' work. (39) The relationship between patient and care giver is a precept of traditional nursing theory. (96) Jean Watson outlined ten principles for nursing, one of which was to establish a helping relationship built on trust, where the nurse communicates and teaches with empathy and respect for the individual. (39) Imogene King's interaction theory describes a process, where the patient interacts with the nurse to enable participation in the planning and execution of care and treatment. (39) Initiatives to increase patients' knowledge and participation by patient education or nursing interventions have proven effective from both a patient and societal perspective. (52, 97) In patients with cardiac disease, individualized nursing interventions have effectively improved patients' HRQoL and disease-related knowledge. (98-100)

2.2.4.1 *Person-centered care*

In efforts to improve patient satisfaction and participation in care, the concept of Person-Centered Care (PCC) has gained increased attention in recent years. (101) In PCC, the patient is viewed as a valued person, an equal partner in care and an expert on living with a chronic condition. In a textbook on person-centered practice, McCormack and McCance (102) propose the following definition of person-centeredness:

Person-centeredness is an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons (personhood), individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development.

By partnering with the patient, the health care staff acknowledges the patient's social, physical and emotional challenges in regard to their health. In an eHealth intervention targeting patients with acute coronary syndrome, combining PCC with shared decision-making and enhanced follow-up improved self-efficacy and functioning, while reducing anxiety and costs of health care. (103, 104) The utilization of PCC is however largely unexplored in vascular surgery.

2.3 MEASURING HEALTH

2.3.1 Health-related quality of life

The most commonly used definition of health was stated by the World Health Organization in 1948:

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

Although the WHO definition of health is still used extensively, it has been criticized as being utopian, and missing the mark for the elderly, living well with stable, chronic conditions. (105) The Health and Medical Services Act acknowledges health as an expression of good living conditions and good health-related quality of life (HRQoL). (106) The concept of HRQoL has gained increasing interest in the planning and prioritizing of health-care resources in recent years. HRQoL can be assessed within a specified patient cohort but can also be utilized in cross-sectional studies and comparisons of different categories of patients, as well as in investigations of the longitudinal health effects of certain treatments. There is a plethora of methods and instruments to assess HRQoL, ranging from generic instruments to assess general health variables in the population, to instruments designed and validated to measure aspects of HRQoL relating to a specific diagnosis or treatment.

Disease-specific HRQoL instruments are constructed to include variables relating to a certain medical condition, which may fall outside the scope of generic HRQoL instruments. This capacity to capture specific traits is described as an instrument's sensitivity. (107) Such instruments often include both physical and psychological aspects distinctive to a certain diagnosis. In clinical research, a generic HRQoL instrument is often combined with disease-specific instruments to attain generalizability to a larger population, while detecting trends in HRQoL in a specified cohort of patients.

2.3.2 Assessing the impact of abdominal aortic aneurysm on health

2.3.2.1 Quantitative evaluations

In vascular surgical care, HRQoL instruments have proven useful in assessing AAA patients' wellbeing at diagnosis, through the surveillance period and adjacent to surgical treatment. (108-110) In studies investigating the effect of AAA screening on HRQoL, no apparent negative effects on HRQoL were found when comparing those with AAA to those with a normal aortic diameter. (111, 112) However, findings regarding the effect of the disease and surgical treatment on HRQoL have been ambiguous. (107, 113, 114) This could in part be explained by the inability of generic HRQoL instruments to differentiate between physical and mental aspects of health, which may be particularly challenging in AAA patients. (115) Patients with AAA experience four different phases during the disease trajectory; 1) diagnosis, which is an unexpected notion of a potentially lethal condition, 2) the surveillance period, with sparse and brief contacts with the health care system for routine examinations of the aneurysm size, 3) the preoperative work-up and surgical treatment and finally 4) postoperative follow-up. For patients undergoing surgery using open repair, follow-up is usually terminated 4-6 weeks postoperatively while patients treated with EVAR are monitored with annual, life-long CT examinations.

Studies on the effect of AAA on HRQoL focus on the different phases of the disease trajectory, and use qualitative or quantitative methods over various time periods. This heterogeneity in methodology, measurements and follow-up has been identified as a limiting

factor to concluding the effect of AAA on HRQoL. (115) In a narrative literature review, assessing HRQoL in men with screening detected AAA, inferior HRQoL was found when comparing to those without AAA and the general population. Following surgical treatment, HRQoL was restored to the levels prior to diagnosis. (115) Comparing the impact of the different surgical treatment methods on HRQoL, the immediate decline in HRQoL is greater in patients treated with OR than EVAR. (116) The same study also found that EVAR patients regain physical and social function sooner than OR patients. This advantage seems to level out over time, and long-term HRQoL assessments favor OR. (109, 117) The impact of AAA diagnosis, surveillance and surgical treatment on the wellbeing of next of kin has not been explored at depth. Due to the increased risk of AAA development in first degree relatives of AAA patients, a AAA diagnosis may potentially affect the wellbeing of siblings and children of AAA patients. This aspect of AAA disease is to date largely unexplored. In qualitative studies, the fear of rupture has been described as limiting patients' wellbeing. (67, 118) With surgical treatment, rupture risk is rectified. This implies that the persistent effect on HRQoL following surgery found in certain studies may pertain to other factors, not fully understood.

In evaluations of the impact of AAA disease and treatment on HRQoL, certain generic instruments are recurring. Medical Outcomes Study 36-item Short Form Health Survey (SF-36) is an instrument used extensively. It covers 8 domains of HRQoL, which can be summarized in two measures, Physical Component Summary (PCS) and Mental Component Summary (MCS). SF-36 is rather comprehensive and several abbreviated versions have therefore been developed, such as SF-12 and SF-8. These have been validated for use in larger cohorts or in combination with other HRQoL instruments and in health economic evaluations. (119) To capture different aspects of HRQoL, generic instruments are often combined, or fortified with study-specific, self-constructed instruments.

The effects of a AAA diagnosis on patients' psychological wellbeing have been debated, and results are somewhat contradictory. (112) Preoperative anxiety is common when patients are planned for major surgery and is associated with increased postoperative mortality and morbidity in cardiac patients. (120) In patients planned for AAA repair, 29% have been reported to suffer from borderline or clinical anxiety. (121) The natural course of anxiety in AAA repair has not been clarified longitudinally. In previous studies, several validated instruments have been used to assess psychological aspects of AAA disease and treatment. One of the most commonly used instruments is Hospital Anxiety and Depression Scale (HADS). HADS aims to measure self-reported symptoms of anxiety and depression in individuals in somatic care. (122) In comparison with other established instruments used to assess psychological symptoms in AAA patients, such as Beck Depression Inventory (BDI) and Spielberger's State Trait Anxiety Inventory (STAI), HADS has been found to be equivalent in identifying symptoms of depression and anxiety. (123)

2.3.2.2 *Qualitative evaluations*

Beyond surgical outcomes described in numerous quantitative studies, patients' perception of the care trajectory and the physical and mental challenges following surgical treatment have been described through qualitative inquiry. In a mixed method investigation of 194 patients at different stages in the clinical management pathway, the provision of explanation and adequate information was described as an important issue to patients. (124) Patients who had undergone surgical repair reported a lack of sufficient information of the severity of surgery and lengthy recovery period. This process, where the physical and emotional impact of AAA surgery gradually sinks in during the recovery period has also been described in a qualitative study with patients having undergone open surgical treatment. (67) Similar findings were presented in a study by Pettersson and colleagues, where participants described feeling unprepared for surgery. (118) The physical and psychological consequences of AAA surgery, with fatigue, sexual dysfunction, loss of appetite and depressive symptoms had not been adequately communicated to patients prior to surgery. In a randomized controlled trial evaluating a leaflet with procedural and sensory information about the disease and surgical treatment, the leaflet had a negative effect on patients' psychological wellbeing. (125) A lack of individual adjustment and psychosocial support was thought to partly explain the findings.

2.4 RATIONALE

In recent years, the implications of adequate and timely information have gained increased attention. To enable patients to prepare and reflect on the consequences of surgical treatment, the timing and individualization of information seems vital. Several studies have also highlighted the potential drawbacks of information, where failure to adjust information to the needs of the patient can cause anxiety and detained participation in care. (112, 125) Although anxiety is prevalent in AAA patients, the consequences of preoperative anxiety on patients' ability to learn and take active part in their care have not been elucidated. Furthermore, the association between learning, psychosocial support and anxiety is not fully understood.

The increasing digitalization within healthcare holds many potential benefits but has major challenges in the implementation process. eHealth interventions tend to be driven by the logic of the health care system rather than the patient. (126) They thereby risk sidestepping the patients' needs and experiences. eHealth interventions have shown promising results in other patient cohorts but is largely unexplored in the care of AAA patients. The knowledge of AAA patients' attitude to modern technology is scarce, and it is not clear whether a targeted eHealth intervention can accommodate learning needs and reduce anxiety in AAA patients. Additionally, several studies have concluded that continuous psychosocial support is needed in the AAA care trajectory but the role and potential of psychosocial support in strengthening AAA patients has not been elucidated.

3 AIMS OF THE THESIS

The overall aim of this thesis was to investigate the need for learning and psychosocial support in patients with abdominal aortic aneurysm (AAA), and scientifically evaluate methods to accommodate these needs in a clinical setting.

The specific aims were:

- Study I.** To describe the perceived learning needs of patients with AAA and to explore their experience of methods for patient education.

- Study II.** To develop and evaluate an eHealth tool for patients with AAA using a participatory design process.

- Study III.** To investigate the effect of an eHealth intervention compared to standard care on anxiety mean scores in patients undergoing surgical treatment of AAA. A secondary aim was to evaluate the effect of the intervention on depression mean scores and HRQoL.

- Study IV.** To explore patients' experience of an eHealth tool and tailored psychosocial support throughout the care trajectory of AAA repair.

4 METHODS

4.1 DESIGNS

The thesis is based on four papers. A broad research approach was used, combining both quantitative and qualitative methods to investigate various aspects of learning, eHealth and psychosocial support in AAA patient, and the effect on anxiety, depression and HRQoL. An overview of the designs and outcomes of the four papers is presented in Table 1.

Table 1. Overview of methodologies in studies I-IV.

Paper	I	II	III	IV
Participants	Individuals previously treated for AAA (n=14)	Individuals with AAA (n=10) and healthcare professionals (n=12)	Individuals undergoing surgical treatment of AAA (n=120)	Individuals with AAA participating in an eHealth intervention (n=12)
Design	Qualitative interview study	Mixed methods	Randomized controlled trial	Qualitative interview study
Data collection period	July 2013 to February 2014	September 2015 to December 2016	November 2016 to March 2020	April 2019 to November 2019
Data analyses	Qualitative content analysis with an inductive approach	Thematic content analysis with a deductive approach, readability assessment using FRES and FKGL	Descriptive statistics, χ^2 test, Student's t-test, Mann-Whitney U test, uni- and multivariate linear regression	Qualitative content analysis with an inductive approach

4.2 SETTING

All studies were carried out at the Vascular Surgery Department at Karolinska University Hospital in Stockholm, Sweden. The Department is one of two centers for vascular surgery in the region and treats a population of 1.2 million inhabitants. At this center, AAA patients are commonly referred either from primary care or the population-based screening program in 65-year old men. They are then kept under surveillance prior to and following AAA repair at an out-patient clinic. Data collection was initiated in 2013 and progressed until 2020. The hospital has one in-patient ward, treating and caring for patients with peripheral vascular disease, including AAA. During the data collection of study III and IV, the in-patient ward moved to a new hospital building. The routine regarding preoperative out-patient visits for information and examination one week prior to surgery remained largely unchanged during the time of data collection. In the old hospital building, the in-patient ward had single, double and three bed rooms whereas the new hospital only provides single rooms. Patients planned

for elective AAA surgery are admitted for in-patient care the night before surgery. The ward is staffed with assistant nurses and registered nurses with and without specialist degrees in surgical nursing, as well as physicians, physiotherapists, occupational therapists and dieticians.

4.3 PARTICIPANTS AND DATA COLLECTION

4.3.1 Paper I

In paper I, all patients who had undergone elective surgery for AAA at Karolinska University Hospital 3-24 months earlier and had attended their 1-month follow-up visit, were evaluated for inclusion. Inclusion criteria were ability to understand and speak Swedish, and signed written informed consent. Individuals with diagnosed cognitive impairment were not deemed eligible for the study. Potential participants were identified through the electronic medical records, contacted via telephone and provided oral and written information. Of 34 approached patients, 14 agreed to participate. Data collection was performed through focus group interviews (FGI). FGI methodology stems from social media and market research, and is used to obtain accurate and relevant data regarding opinions, perceptions, experiences and attitudes through group discussions. (127) During a FGI, the interviewer facilitates and enables discussions between the participants, normally utilizing an interview guide to provide a framework for the conversations. Discussions among the group members allow for observations on individual views, as well as how individual views are perceived, confirmed or rejected by other group members. (128)

As the two available surgical treatments for AAA differ in management and recovery, two FGIs were assembled with OR and EVAR patients respectively. To capture attitudes and aspects of information pertaining to risks and complications, a third FGI was performed with patients who had experienced complications following surgery. Purposeful sampling was applied to achieve heterogeneity in sex, ethnicity, age, and civil status. The scope of the FGIs was the time period from initial diagnosis throughout surveillance, surgical treatment and postoperative follow-up. The interviews were conducted by an interviewer and attended by a moderator, and varied between 70 and 120 minutes in length. The focus group methodology allows participants to confirm, reject or comment on what the other participants are expressing. This enables a natural probing of the participants' descriptions, providing immediate data validation in the process of data collection. (128) The interviewer aims to facilitate and stimulate discussion rather than directing it. In the current study, a semi structured interview guide was used to provide a general framework for the interviews, while allowing for variations in the dynamics of the groups. Open-ended questions were used to enhance the internal interactions of the groups and probing questions were utilized to enable participants to elaborate or clarify. (96) The interview guide was designed by the authors, based on scientific evidence regarding surgical patients' information needs and principles of

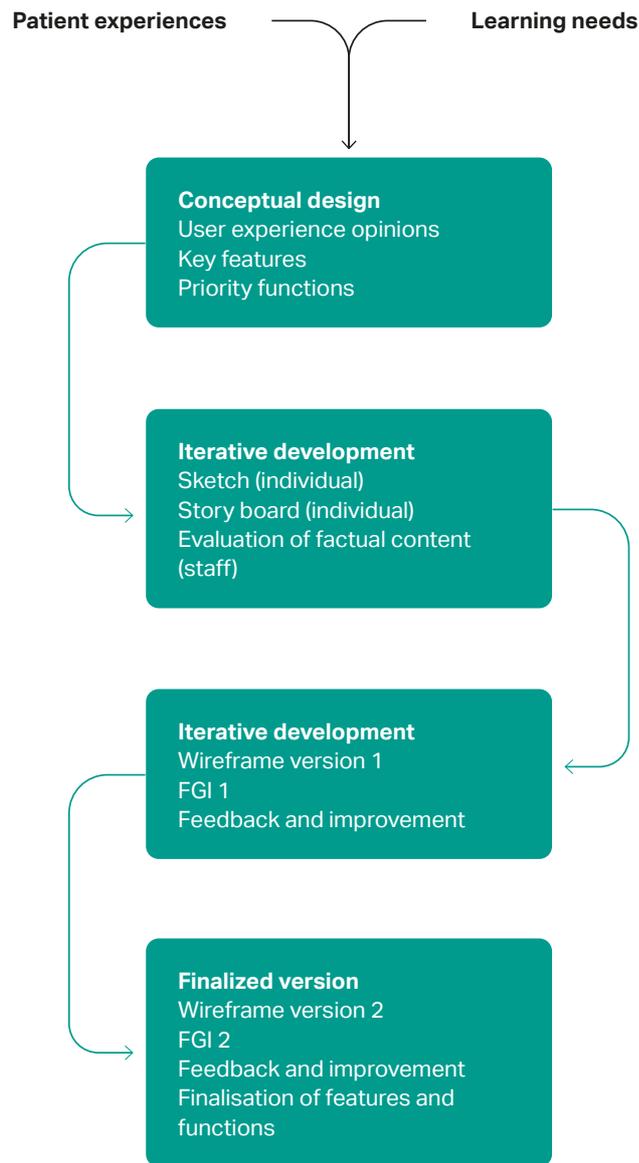
patient education in surgical nursing care. (40, 67) It was also reviewed by two senior professors in qualitative research.

4.3.2 Paper II

4.3.2.1 Development of an eHealth tool for AAA patients

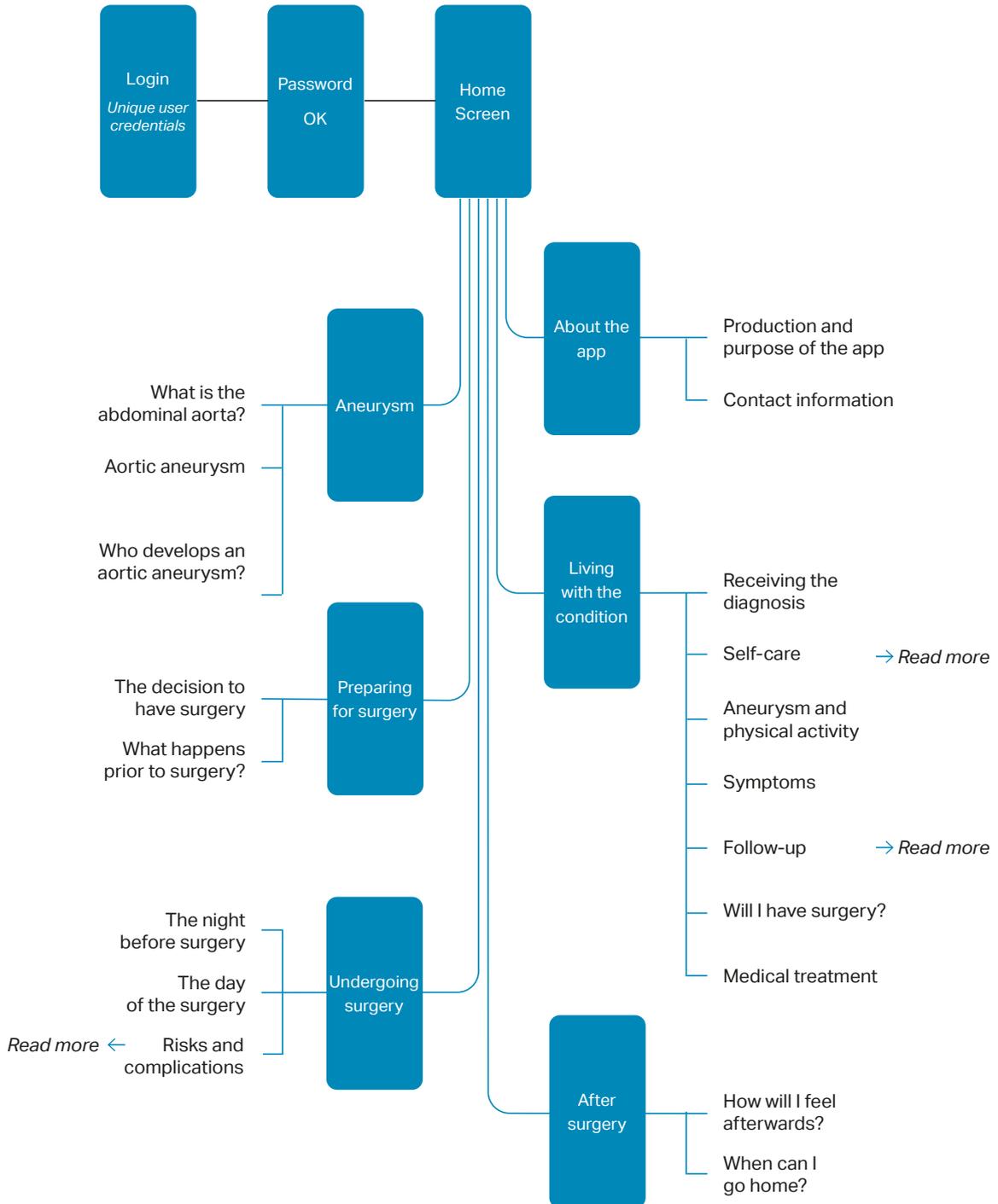
To provide patients and next of kin with structured, factual information regarding the condition and the care pathway, an eHealth tool was developed using participatory design (PD) methodology. The content and structure of the eHealth tool *My aorta*, evolved over several years, and was reassessed as the studies progressed. Front end and back end mobile application developers, patients and health care staff were involved during the different phases of development. The first phase of product development included a needs assessment which resulted in paper I, where the learning needs of AAA patients were explored and described. The following two phases of development involved generating ideas and prototypes, and testing and developing these for implementation. These phases are described in paper II. The fourth and final phase included testing and validating the end product in a real-life setting, where quantitative findings are described in paper III and qualitative aspects are described in paper IV. In paper I, different information formats were warranted, and the personal contact with health care staff was highly valued. The eHealth tool was therefore intended to complement the current information regime at the department, potentially enhancing the format and time points for learning and preparing for the surgical treatment and postoperative recovery. During the conceptual design phase, participatory design workshops were held individually with three patients scheduled for AAA repair. The results guided the development of features and functions in the pilot version of the tool, this phase is not outlined in detail in paper II. A wireframe version was then developed with a visual, interactive representation of the pilot version of the eHealth tool. The medical and nursing content of the eHealth tool was based on current patient education material about the disease and surgical treatment, and relevant published literature. (18, 129) The tool was designed to convey a balanced amount of information regarding rupture risk and surgical risk. It included 2-D graphics, illustrations, pictures and text on screen. The interface was designed to appeal to older patients, including those with limited experience of modern technology. It could be accessed with tablets, smartphones and computers. The output of each activity constituted the input into the next activity. Details of the conceptual design and participatory design process are outlined in Figure 2.

Figure 2. Design and development process of the eHealth tool.



The application was built in 2015 and 2016. To achieve a stable product for use in the patient cohort, the eHealth tool was launched on App Store and Google Play to allow for download to both iOS and Android. The home screen consisted of icons with captions representing the different chapters. Clicking on an icon, a drop-down menu presented the sections of each chapter. The tool was designed for users to navigate freely and read the sections of interest. There were no time triggers directing the speed with which the users browsed through the tool. Some sections contained additional, in-depth information that the users could access if required. The eHealth tool comprised six chapters. The first chapter contained practical information about the project and the eHealth tool, as well as contact information. The additional five chapters each had different themes relating to the condition: ‘aneurysm disease’, ‘living with the condition’, ‘preparing for surgery’, ‘undergoing surgery’ and ‘recovering from surgery’. The structure of the eHealth tool is described in Figure 3.

Figure 3. Structure and content of the eHealth tool.



4.3.2.2 *Participants and data collection in paper II*

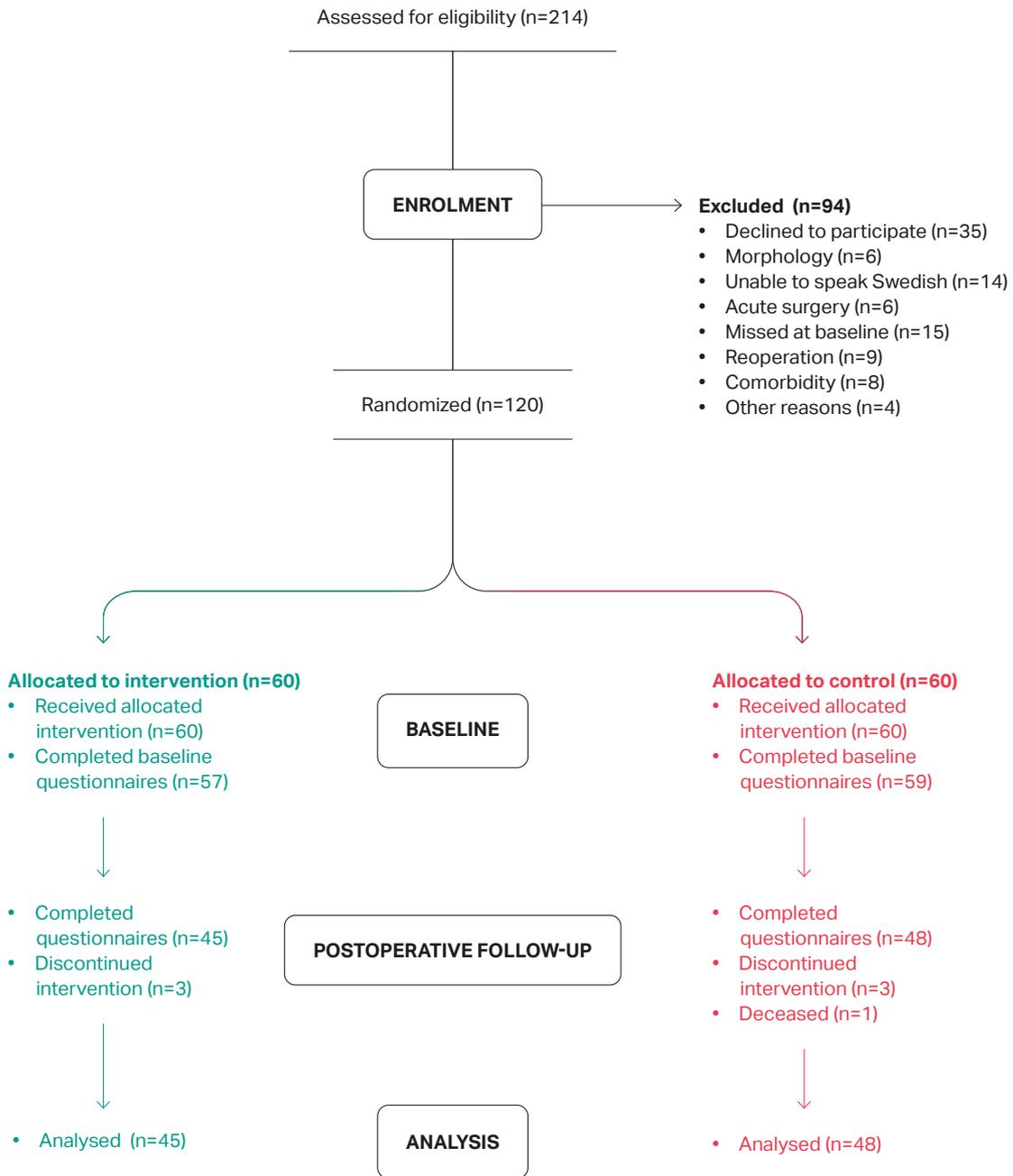
In paper II, the time frame from surgery was narrowed to 3-12 months, to enable more detailed recollections of participants' experiences of the surgical care trajectory. This was anticipated to enhance the quality of data regarding the accuracy and relevance of the eHealth tool. The factual contents were evaluated by health care professionals with at least two years' experience of treating and caring for AAA patients. Six specialized vascular surgeons and eight registered nurses participated. As in paper I, purposeful sampling was applied.

A study-specific, self-constructed questionnaire with open-ended questions was used to validate the contents of a piloted eHealth tool among health care staff. The questionnaire was administered with a mock-up of the eHealth tool in the form of printouts of the text content and illustrations. The questionnaire is not presented in the manuscript. A readability analysis was also conducted using the validated measures Flesch Reading Ease Score (FRES) and Flesch-Kincaid Grade Level (FKGL). Two focus group interviews (FGIs) were then conducted, with iterations and updates to the pilot version of the eHealth tool between the two FGIs. A semi structured interview guide was used, with three themes; platform design, terminology and content, and accessibility. Each participant was provided with a tablet containing a pilot version of the eHealth tool, to capture usability aspects.

4.3.3 **Paper III**

All patients scheduled for AAA repair between November 2016 and February 2020 were considered for inclusion in **study III**. Potential participants were identified from the surgical waiting list and were contacted via telephone if they fulfilled the following inclusion criteria: age >50 years, scheduled for elective surgical treatment of an infrarenal aortic aneurysm. Cognitive impairment, severe visual or hearing impairment, inability to speak or understand Swedish, juxta-/suprarenal or thoracoabdominal aneurysms or severe comorbidity with estimated survival <1 year were considered exclusion criteria for the study. Eligible participants were contacted via telephone and provided oral and written information. Informed consent was obtained at the preoperative outpatient visit, usually one week prior to surgery. In some cases, where patients were referred from another county for surgical treatment, informed consent was obtained the day before surgery. Enrolment and study procedures are described in Figure 4.

Figure 4. Flow diagram describing enrolment, intervention, follow-up and analysis.



Study procedures are described in Table 2. The control group received information and follow-up according to standard clinical routine, with verbal preoperative information by a vascular surgeon, anesthesiologist and registered nurse and a leaflet containing information about the surgical procedure and general recovery advice. The intervention group received standard care augmented with an intervention comprising two parts: an eHealth tool, and structured psychosocial support by a registered nurse to guide the participants through the peri- and postoperative period. The eHealth tool My aorta could be accessed via a smart phone or tablet but was also made available as a print-out for those who preferred paper format. The participants were offered to borrow a tablet free-of-charge during the study

period. Participants in the intervention group were offered access to the eHealth tool and those who accepted were assigned unique, password protected login credentials through a web-based user management system. The content of the tool was adjusted to the planned surgical treatment (EVAR or OR).

Table 2. Study procedures in paper III.

Visit	Baseline	Discharge	Follow-up
Time window (days)	1-7 days prior to surgery	Not applicable	1 month postop \pm 7 days
Informed consent	X		
Demographic data ^a	X		
Medical history and clinical examination ^b	X		
Hematology ^c	X		
Concomitant medication	X		
Administration of eHealth tool (intervention group only)	X		
Psychosocial support session (intervention group only)	X	X	
Questionnaires ^d	X		X
Adverse event monitoring		X	X

^a Age, sex, civil status, education level. ^b Current medical conditions and medical history, blood pressure, ankle-brachial index, pulse, height and weight. ^c Creatinine (mmol/L). ^d HADS and SF-12.

Participants in the intervention group were assigned a contact nurse and received an orientating, psychosocial support session. The psychosocial support stemmed from the concept of person-centered care (PCC), and the three registered nurses who carried out this part of the intervention had all been trained in PCC. The initial session was aimed to establish a trusting relationship, and determine the participant's anticipations, needs and concerns when facing surgery. The content of the sessions was not fixed, but could entail both practical, emotional and existential aspects of AAA surgery. The sessions were documented in the participants' medical journal, and a follow-up session took place prior to hospital discharge. These sessions were not timed and the specific contents of the conversations were not analyzed in depth. However, specific questions or concerns that warranted further action were noted and dealt with accordingly. Contact information was provided and participants in the intervention group were encouraged to reach out to their contact nurse if questions or concerns arose. Follow-up questionnaires were completed at the postoperative visit to the outpatient clinic, usually at 4-6 weeks after surgery.

4.3.4 Paper IV

In **paper IV**, a subset of participants from the intervention group of **study III** were approached via telephone and informed about the study. Purposive sampling was used to attain a representative subset of participants from the intervention. Of 23 participants who received information about the study, 12 were finally included. To gain an increased understanding of the factors influencing the decision to use the eHealth tool or not, both participants who had utilized the tool (n=7) and those who had not (n=5) were interviewed.

To deepen the understanding of the participants' perception of the intervention, an inductive approach was chosen. Individual, in-depth interviews were performed in an administrative hospital setting during 2019. A semi-structured interview guide ensured stringency throughout the interviews and probing questions were used to enable informants to deepen or clarify their reasoning. Data was collected until saturation was reached, and sufficient source for analysis was settled.

4.4 OUTCOMES AND INSTRUMENTS

4.4.1 Interview data

In **paper I, II and IV**, interview data were collected. During the focus group interviews (FGI) and the individual interviews, a dictation machine was used for audio recording through the program software Audacity™ version 2.0.5.0. Audio files were saved in mp3 format and all interview data was transcribed verbatim. The main instrument for data collection in qualitative inquiry is the interview guide, which affects the level, depth and richness of data. (96) Semi-structured interview guides aim to maintain consistency in the interviews, while still allowing for in-depth elaborations and embellishments. To minimize researcher bias, narrative interviews with less structure and guidance may be beneficial. (96) A narrative approach requires that participants have a clear view of the scope of the interviews and may result in inconsistent data and a cumbersome analysis process. Patients' experiences of AAA diagnosis, surveillance and surgical treatment has in part been explored previously in qualitative studies. Semi-structured interview guides based on current evidence and the specific aims of the different papers was therefore chosen for data collection.

4.4.2 Sociodemographic and comorbidity data

Data on sociodemographic parameters and comorbidity were mainly retrieved from electronic medical records at baseline. Pharmaceutical use was registered at the patients' preoperative out-patient visit. Clinical data in **study III**, e.g. blood pressure, ankle-brachial index and blood sample results were registered at baseline, or at a prior visit to the vascular outpatient clinic within three months. If patients had an ongoing medication for a medical condition, such as COPD or hypertension, the medical condition was registered whether or not it was

mentioned at the preoperative examination. Current daily smokers and sporadic smokers were considered current smokers whereas those with more than four weeks abstinence were considered as previous smokers. Coronary heart disease was defined as a composite of previous ischemic events, diagnosed pectoral angina or diagnosed congestive heart failure.

4.4.3 Validated instruments and self-reported questionnaires

In **paper II**, readability of the eHealth tool was assessed using **Flesch- Reading Ease Score (FRES)** and **Flesch-Kincaid Grade Level (FKGL)**. FRES calculates syllable content and sentence length to assess the language difficulty of a specific reading passage. (130) It generates a score which correlates to language complexity. Texts that are easy to read generate higher scores. The FKGL formula is based on the FRES parameters and creates an estimate of the grade level (years of education) required to fully understand a text segment. (131) The American Medical Association (AMA) recommend that patient education materials should be written on a 5th to 6th grade level. (132) This was therefore the level we set out to achieve in paper II.

In **paper III**, participants were asked to complete the same questionnaires on two occasions, first at the preoperative outpatient visit (usually one week prior to surgery) and at the postoperative follow-up visit to the outpatient clinic (at 4-6 weeks postoperatively). If the questionnaire was not returned, one reminder was sent by post. An outline of the instruments' items and alpha values are shown in Table 3.

Table 3. Self-reported questionnaires (paper III)

Instrument	Measure	Items	Range	Direction	Alpha†	Reference
HADS	Psychological status	14	0-3	↓ fewer symptoms of anxiety/depression	0.81-0.92	Djukanovic et al., 2017
SF-12	HRQoL	12	1-5	↑ better mental and physical HRQoL	0.73-0.86	Jakobsson, 2007

† Lowest and highest alpha value from subscales.

Based on the results from **paper I** and **II**, as well as other qualitative studies regarding perioperative anxiety in AAA patients, the **Hospital Anxiety and Depression Scale (HADS)** was chosen as the primary outcome measure to assess symptoms of anxiety and depression. The instrument consists of two subscales: HADS Anxiety (HADS-A) and HADS Depression (HADS-D). The two subscales HADS-A and HADS-D were used to assess anxiety and depressive symptoms respectively, hence the total score was not reported or analyzed across treatment groups. Each subscale has seven claims, evaluating the respondent's self-perceived

psychological state during the past seven days. Answers are given on a four-digit Likert scale, ranging from 0 to 3 points and each subscale is summarized with a maximum of 21 points. Higher scores indicate more severe symptoms. Seven points or less on each subscale indicate an absence of depressive or anxiety symptoms of clinical significance. (122) HADS scores between 8 and 11 are classified as borderline, whereas scores of 12 and above represent significant depressive or anxiety symptoms. A cut-off score of ≥ 8 gives a specificity of 0.78 and a sensitivity of 0.9 for clinical anxiety (HADS-A) and a specificity of 0.79 and a sensitivity of 0.83 for clinical depression (HADS-D). (26) HADS has good internal consistency and validity to assess psychological distress in a population aged 65-80 years and was there deemed an appropriate instrument for AAA patients. (133)

The **12-item Short-Form health survey (SF-12)** is a well-known HRQoL instrument, which has been used extensively in cardiovascular research. It derives from the widely used SF-36 instrument, and has been translated and validated for Swedish contexts. (134) The instrument consists of 12 items, grouped under eight dimensions of health. Results of the SF-12 are presented as summary scores in two dimensions, physical component summary (PCS) and mental component summary (MCS). These values follow a standard T distribution where the population presents with a mean of 50 and higher scores indicate better HRQoL. (119) In assessments of HRQoL in patients aged 75 to 79 years old, mean scores were 41.6 and 52.1 for PCS and MCS respectively. (135) The instrument is advantageously short compared to other HRQoL instruments and produces robust estimations of physical and mental health aspects in the older population. (135)

4.5 DATA ANALYSES

4.5.1 Qualitative analysis

A qualitative design was used in **studies I, II and IV**. Different analysis methods were chosen depending on the inquiry. Generally, interview data is analyzed through qualitative content analysis. Content analysis has a long history of use in various disciplines such as communication, sociology, psychology. Content analysis is a research method which describes and explores phenomena in a systematic and objective manner. (136) The outcome of a content analysis can be presented as themes, categories or concepts, depending on the chosen approach to data analysis. (136) In **paper I and IV**, a content analysis with an inductive approach was chosen. This approach is suitable to investigate or explore a situation or phenomenon of which no evident hypothesis has been formulated. As outlined by Elo and Kyngäs, this approach entails five steps. (137) First, each interview is read repeatedly, to identify recurrent patterns and tendencies. Words and phrases pertaining to the aims of the study are then marked, color-coded and separated. The text units are then condensed to meaning units, such as words or phrases carrying an important meaning or essence. These are then labeled with a code. In the fourth step, codes are grouped to form subcategories. Lastly,

the subcategories are assembled into categories. Throughout the analysis, comparisons are made between categories, codes, meaning units and the original data to avoid alienation from the original interview data. During the content analysis process, findings are discussed within the research group until consensus regarding the final analysis is reached.

A deductive approach is preferred when testing existing data in a new concept, or to test hypotheses. (137) This approach was chosen in study II, using a thematic content analysis where the aims were not primarily exploratory. A categorization matrix was utilized during the analysis, with categories consistent with the three themes of the interview guide. Data was then reviewed for content and coded for correspondence with the predefined categories. The analysis comprises three steps, preparation, organization and reporting. Meaning units were identified, coded and subcategories were formed. (138) Irrespective of the chosen approach, a basic premise for categories and subcategories resulting from a content analysis is the internal homogeneity and external heterogeneity of categories and subcategories. (136)

4.5.2 Quantitative analysis

4.5.2.1 Statistical analysis

In **study III**, all participant related data were continuously recorded in a local registry and anonymized prior to analysis. For quantitative analysis, SPSS (version 26) software was used. Analyses were also performed in Stata (Version IC.16.1 Stata Corp, College Station, TX) when performed in collaboration with statistician (M.Kotopouli, IMM, KI). χ^2 test was used to compare categorical variables and independent *t* test to compare continuous data. For comparisons of independent groups, Student's *t* test was used for normally distributed data, and Mann-Whitney was used for non-parametric data. Spearman's correlation was used to study the association between ordinal variables, such as educational level. Continuous variables were presented as means (SD), and categorical variables were presented as counts and proportions as appropriate. Primary analysis was performed per intention-to-treat for control group versus intervention groups. Secondary, per protocol analyses were performed. A *p*-value of <0.05 was considered statistically significant. Comparison of the changes in HADS-A from baseline to the postoperative follow-up between the treatment groups was used as the main dependent variable in the primary analysis.

4.5.2.2 Sample size estimations

The sample size calculation in study III, estimated that 45 persons should be invited in each treatment arm to detect a 50% difference in the HADS-A mean scores between control and intervention group at the postoperative follow-up (with 80% power, 5% significance level). Due to an estimated 20% internal attrition, 60 were included in each treatment arm. *P* <0.05 was considered statistically significant.

4.5.2.3 *Clinical significance*

To convert data from the intervention to the clinical situation, a measure of the minimal clinically important difference (MCID) was used. MCID is defined as the smallest change in a treatment outcome that is of clinical significance. (139) In making inferences from measures, MCID is not synonymous with statistical significance and implies that an intervention may provide clinically meaningful results even in the absence of statistical significance. For estimations of the effect of the intervention in **paper III**, the MCID of the primary outcome measure, HADS-A, was sought. In distribution-based estimations of cohorts of patients with cardiovascular disease, HADS-A MCID values of 1.67 points for within-patients measurements and 1.29 for between-patients measurements have been identified. (139) In patients with COPD, even lower MCID values of 1.32 points for HADS A have been established. (140) In the analysis of **study III**, a within-group change in HADS-A mean scores of 1.67 and 1.29 between treatment groups was therefore considered clinically significant.

4.5.3 **Missing data**

Missing data can refer to clinical examinations, sociodemographic variables, questionnaire or other sources of study data. In **paper III**, a missing questionnaire was regarded as a non-responder in that specific point of measurement, and these questionnaires were not included in the analysis. In cases of missing responses within a returned questionnaire, imputations can be considered. According to the scoring manual of SF-12, imputations are not recommended as the instrument is a condensed version, derived from the SF-36. (119)

4.6 **ETHICAL CONSIDERATIONS**

The studies included in this thesis conformed to the Helsinki declaration (141). It is the duty of the researcher to promote and safeguard the health of those involved in medical research, and to be guided by the ethical principles of autonomy, non-maleficence, beneficence and justice (142). In the process of collecting, handling, analyzing and presenting data, precaution was taken to protect the privacy and confidentiality of the participants and their personal information. All research was evaluated and approved by the regional ethics committee in Stockholm; **study I** and **II** (Dnr: 2013/788-31/4 and 2014/151-32/4), **study III** (Dnr: 2016/1253-31/4) and **study IV** (Dnr: 2016/1253-31/4 and 2018/24-32). Patients were given verbal and written information in due time, to enable them to contemplate and make an autonomous choice whether to participate in the study or not. Written informed consent was obtained from all participants prior to inclusion. Participants were also informed of their right to withdraw from the studies at any time. All study procedures were free of charge and to

safeguard participants' independence and neutrality, they were not offered financial compensation for their participation in the studies.

Measures were taken to preserve the patients' autonomy, which in the healthcare setting involves individual choices, privacy and retaining one's own identity. (143) Patient autonomy can be viewed as a multidimensional concept, where decisional, executive, functional, informative and narrative autonomy can be confined in the interaction between patients and health care staff. (143) The authority of health care staff can confine the patient's capacity to exercise autonomy. This risk should be acknowledged both in clinical care and in the research setting. This thesis focuses on tailoring eHealth and psychosocial support to patient needs, to minimize distress and maintain autonomy during the care pathway of AAA treatment. When patients face a life-altering experience, such as undergoing major surgery, the gratitude they may feel towards health care staff may lead them to feel pressured to participate in clinical research. This social desirability may have affected their decision to participate. For this reason, potential participants were repeatedly informed of their right to decline participation without any consequences for their care.

When performing clinical research, it is pivotal that data collection does not interfere with or negatively impacts the care of the patient. In **studies III** and **IV**, great care was taken before and during the data collection to minimize the impact of the study on participants' physical, mental and social integrity. The number of questionnaires in **study III** were carefully considered prior to study initiation. Even so, participants perceived the number of questionnaires as burdensome. To safeguard the participants' capacity for rehabilitation and self-care in the postoperative phase, the time points and details of data collection were revised accordingly.

In qualitative research, individual interviewing requires a delicate approach to preserve the participants' integrity. In **study I, II** and **IV**, participants were therefore informed of the psychological impact that the interview may evoke and were offered emotional support when warranted. To maintain participants' anonymity throughout data analysis and presentation, unique codes were used. Participants' integrity was also taken into account in decisions regarding the citations presented, not to reveal personal information that may jeopardize their anonymity.

5 RESULTS

5.1 PARTICIPANTS

A total of 144 patients were recruited in the different studies. In addition to the patients recruited to **study II**, 12 staff members (6 vascular surgeons and 8 registered nurses) at the Department of Vascular Surgery also contributed to the development of the eHealth tool. Participants in **study IV** were recruited from the intervention group in **study III**. An overview of the participants in the different papers are presented in Table 4.

Table 4. Demographic and clinical characteristics of participants in study I-IV.

Variable	Study I (n=14)	Study II (n=10)	Study III (n=120)	Study IV (n=12)
Sex				
Male	12	9	104	9
Female	2	1	16	3
Age, median (range)				
	75 (66-85)	69 (58-78)	72 (52-93)	72 (53-86)
Living situation				
Married/living with partner	8	8	86	8
Living alone	6	2	34	4
Education level				
Junior compulsory	-	-	28	0
Senior high school	-	-	51	6
Postgraduate/university	-	-	39	6
Occupation				
Working	2	3	25	4
Retired	12	7	95	8
Risk factors and comorbidities				
Cancer	2	1	19	2
Hypertension	9	10	92	10
Diabetes mellitus	2	1	25	2
Coronary artery disease	9	6	26	1
Previous stroke	1	3	16	2
COPD	4	2	41	5
Renal failure	2	1	12	3
Surgical treatment method				
OR	5	4	57	8
EVAR	9	6	63	4
Months since surgery, median (range)				
	12 (4-21)	10 (3-17)	-	4 (3-13)

COPD = chronic obstructive pulmonary disease; OR = open repair; EVAR = endovascular aortic repair.

5.2 PATIENTS' NEED FOR LEARNING AND SUPPORT

Different aspects of patients' need for learning and psychosocial support were described in **paper I, II and IV**. In **paper I**, patients described their learning needs through the care trajectory of AAA disease, from initial diagnosis, through the surveillance period and in conjunction with surgical treatment and postoperative follow-up. The learning needs described in **Paper II** were expressed in regard to the pilot version of the eHealth tool whereas the results of **paper IV** pertained to the participation in the eHealth intervention.

5.2.1 Learning needs

In **paper I**, learning needs pertained to risks and complications with surgery, self-care, and rupture risk. In learning situations, patients refrained from asking questions as health-care staff was often perceived as stressed and overstrained. Patients did not experience that their learning needs were attended to, and they therefore relied on other sources of information such as the internet or anecdotal information from family and friends. Learning was described as a process of self-guided information seeking, where they utilized their previous experiences of health care encounters as a basis onto which new knowledge could be added. Curiosity was identified as the major driving force in the learning process.

The discrepancy between the contents of the department's standard information provided to the participants prior to surgery, and the contents of the eHealth tool was described in **paper II**. Based on this, participants warranted more information about sex differences, hereditary factors, postoperative mobilization, pain management, sexual function and concurrent aneurysms. Patients treated with open repair described being startled by the postoperative malaise. Even if they had been informed, they had not comprehended the extent of the lassitude and fatigue that followed surgical treatment.

In **paper IV**, the aim was to explore patients' experience of an eHealth tool and psychosocial support. However, the results also pertained to patients' learning needs in relation to an eHealth intervention. The eHealth tool enabled autonomous learning, where the participant could determine the timing and amount of information based on their learning needs at different phases during the care trajectory. The potential of adjusting the eHealth tool to the specific learning needs of the end-users was also raised, and further flexibility and individualization was asked for. As the eHealth tool was provided as an add-on to the verbal and written information prior to surgery, some participants perceived the overall amount of information as overwhelming. In these situations, they sometimes found it difficult to prioritize and instead refrained from assimilating information. Negative encounters with health care staff affected patients beyond that specific situation and could harm their sense of trust in the health care system. A need to understand and grasp the experience of undergoing surgery was described in the postoperative phase after discharge, as the perioperative anxiety had eased. In these cases, the eHealth tool proved useful. In learning situations, participants mediated conversations and asked questions to match their learning needs. Health care staff

were responsive and most often adjusted the content and amount of information to the needs of the patient.

5.2.2 Delivering risk information

Patients' ambivalence regarding the timing and content of risk information was expressed in both **paper I, II and IV**. Verbal risk information at times caused distress, and disrupted patients' ability to participate in learning situations such as the preoperative out-patient clinic visit. Despite the potential negative psychological effects of risk information, patients valued that health care staff did not withhold information. By providing risk information, health care staff was perceived as honest and trustworthy. In **paper II**, the risk information in the eHealth tool was perceived as more extensive than the verbal and written information that participants had received prior to surgery. Participants requested individualization of risk information, as some were believed to experience risk information as intimidating. As opposed to the findings in study I, participants in **paper IV** described face-to-face conversations as most appropriate for discussing sensitive matters such as risks and complications.

5.2.3 Psychosocial support

In **paper I**, a requisite for professional psychosocial support was expressed. Whether patients were diagnosed through population-based screening or incidentally, the AAA diagnosis caused immediate distress in patients and next of kin. Continuous personal contact with a trusted health care staff with experience within the vascular surgical field was thought to be beneficial. Lacking someone to turn to with questions aggravated patients' anxiety and caused feelings of abandonment. Accessibility to health care alleviated patients' sense of unease. This viewpoint was also raised in **paper IV**, where even short telephone conversations or the notion of being able to call their contact nurse contributed to participants' sense of being cared for. The need for psychosocial support sometimes became evident in retrospect, as participants reflected upon the care trajectory. At times, psychosocial support by health care staff allowed participants to elaborate more freely on existential and psychological aspects of AAA surgery than through conversation with next of kin. Dreading the stress that their own anxiety may impose on next of kin led patients to contain certain thoughts, and distance themselves from friends and family.

5.3 DEVELOPMENT AND EVALUATION OF AN EHEALTH TOOL

After the needs and requisites of the end uses had been identified, the eHealth tool was developed and validated through two additional phases of participatory design (PD):

generating ideas and prototypes, and testing and developing prototypes for implementation. The content of the eHealth tool was based on current local and regional patient education material and current guidelines regarding patient education. The text content and illustrations were evaluated regarding accuracy, relevance and content by six specialized vascular surgeons and eight registered nurses with more than 2-year working experience of treating and caring for AAA patients. A self-constructed, purposively developed survey instrument was used, and results were analyzed using manifest qualitative content analysis. The factual content and illustrations were perceived as sufficient, but a broad spectrum of opinions regarding information on risks and complications with surgical treatment was raised. While some perceived it as too superficial, others thought it was excessively detailed. Inconclusive opinions regarding the relevance of providing numerical statistics were expressed.

5.3.1 Language and readability

The language and readability of the eHealth tool was assessed from different perspectives. Health care staff expressed that the language level in the pilot version of the eHealth tool corresponded to the language used in clinical encounters with patients. In the FGIs, patients having undergone surgical treatment expressed that the language was consistent, understandable and adequate. However, the results of the readability analysis using validated instruments exceeded the reading levels recommended for patient education material. After revision, the mean Flesch Reading Ease Score (FRES) was 42.2, corresponding to texts on college level. Flesch-Kincaid Grade Level (FKGL) was set to a maximum of 8. Despite several revisions to enhance readability, the overall mean FKGL in the final version of the eHealth tool was 10. Thereby, none of the chapters reached the target levels for neither FRES nor FKGL.

5.3.2 Design and interphase

The eHealth tool was designed to appeal to older patients, with large and distinct visual elements, large font size and illustrations. This was also reflected in the interphase design by avoiding complex gestures and enabling free navigation without time-triggers or other restrictions. In the focus group interviews evaluating the overall structure and user interphase, a majority could enter, navigate and explore the eHealth tool without specific instructions or assistance. The eHealth tool was perceived as intuitive and self-instructive. Nevertheless, participants expressed that the simple user interphase may be of little help to those who have a low technological self-esteem, who may not even consider using the eHealth tool. To enhance usability, adaptation to those with visual or hearing impairments was also emphasized.

5.4 PATIENTS' ATTITUDE TO EHEALTH

In **paper I**, different information formats were believed to facilitate or hamper learning. Written information with appropriate illustrations, followed by a personal contact, was

considered beneficial from a learning perspective. Modern technology such as the internet was used for information seeking, but available online information was not always found to be relevant. In **paper II**, several advantages of eHealth were described, such as remote access to information, the possibility of individualization and adjustment to increase accessibility among patients with visual or hearing impairments. The possibility of adjusting the timing of information to one's needs was also brought forward as a potential advantage. It was hypothesized that older patients may be hesitant and unconfident to use eHealth. This notion was confirmed in **paper IV**, where non-users of the eHealth tool described being limited by a low technological self-esteem.

One predisposing factor for patients to utilize the eHealth tool was personal experience of modern technology, those with limited experience of modern technology declined to use the eHealth tool. Other reasons for rejecting the eHealth tool were lacking interest and financial shortcomings. Participants described that the eHealth tool alleviated their responsibility for informing next of kin. The imbalance in knowledge between patients and next of kin at times caused stress and the notion of receiving information from the same source, through the eHealth tool, was appealing.

5.5 THE EFFECTS OF AN EHEALTH INTERVENTION

5.5.1 Participant characteristics

Out of the 214 patients deemed eligible for the study, 120 were included with 60 participants in each treatment arm. Within the intervention group, 30 participants (50%) chose to utilize the eHealth tool and the remaining 30 participants received standard care, psychosocial support and a leaflet with information from the eHealth tool. There were no significant differences in baseline characteristics between the control and intervention group. A majority of participants were male (87%) and previous or current smokers (91%). A higher proportion of participants in the control group had a history of coronary heart disease, but all other comorbidities were similar between the groups. Baseline levels of anxiety and depression symptoms measured by HADS-A and HADS-D mean scores were similar between the groups. Female participants had higher HADS-A mean scores than men at baseline (5.53 vs 4.06, $p=0.167$) and a larger proportion was planned for open repair (68% vs 44% of the male participants).

5.5.2 Effects on symptoms of anxiety

Intention-to-treat and per protocol analyses of differences in HADS-A are presented in Table 5. In the crude analysis of HADS-A mean scores, no statistically significant difference could be detected between the groups from baseline to postoperative follow-up. However, the

hypothesized reduction in anxiety mean scores of 50% in the intervention group was surpassed and amounted to -0.667 between the control and intervention group. In the primary analysis, neither the sought minimal clinically important difference (MCID) of 1.29 points between the treatment groups nor the within-group reduction of 1.67 was thereby reached.

Table 5. Changes between baseline and postoperative scores regarding HADS-A. Subgroup analysis on participants in the intervention group by the use of the eHealth tool, educational level, sex and surgical technique are also presented.

	Mean change in HADS-A Baseline to postop		Mean difference between groups (95% CI)	P ^a	
	Control	Intervention			
Crude analysis	-0.542	-1.209	0.668 (-0.70, 2.03)	0.334	
Age					
≤ 69	-1.423	-2.000	0.571 (-1.79, 2.94)	0.536	
70–79	-0.265	-1.227	0.963 (1.09, 3.01)	0.382	
≥ 80	-1.000	0.125	1.125 (3.62, 1.37)	0.592	
Educational level					
Junior compulsory	-0.417	1.600	-2.017 (-4.92, 0.89)	0.218	
High school	-0.227	-1.833	1.606 (-0.17, 3.38)	0.028*	
University	-1.143	-2.333	1.190 (-1.52, 3.90)	0.673	
Surgical technique					
OR	0.167	-1.636	1.803 (-0.82, 4.42)	0.117	
EVAR	-0.967	-0.762	0.205 (-1.63, 1.22)	0.900	
Sex					
Men	-0.465	-0.943	0.478 (-1.01, 1.97)	0.319	
Women	-1.200	-2.375	0.175 (-2.91, 5.26)	0.767	
Use of the eHealth tool	Control	App users			
	-0.542	-2.000	1.458 (0.16, 2.76)	0.028*	
Use of the eHealth tool		Non-users	App users		
	-	-0.210	-2.000	1.789 (-0.71, 4.29)	0.051

^a Analysed with Mann-Whitney.

In the per protocol analysis, clinically significant differences were found in both within-group and between-group estimations. In the intervention group, the sub group of participants who received the complete intervention comprising the eHealth tool and psychosocial support had a greater reduction in HADS-A mean scores than the control group (-0.54 in the control group vs -2.0 for app users in the intervention group, $p=0.028$), illustrated in Figure 5. In analyses within the intervention group, users of the eHealth tool reported a larger reduction in HADS-A mean scores than non-users (-0.21 non-users vs -2.00 app users, $p=0.051$). Larger reductions in HADS-A mean scores were noted in younger patients, and those with higher educational level (Figure 6 and 7).

Figure 5. HADS-A mean scores at baseline and follow-up for control group, users and non-users of the eHealth tool.

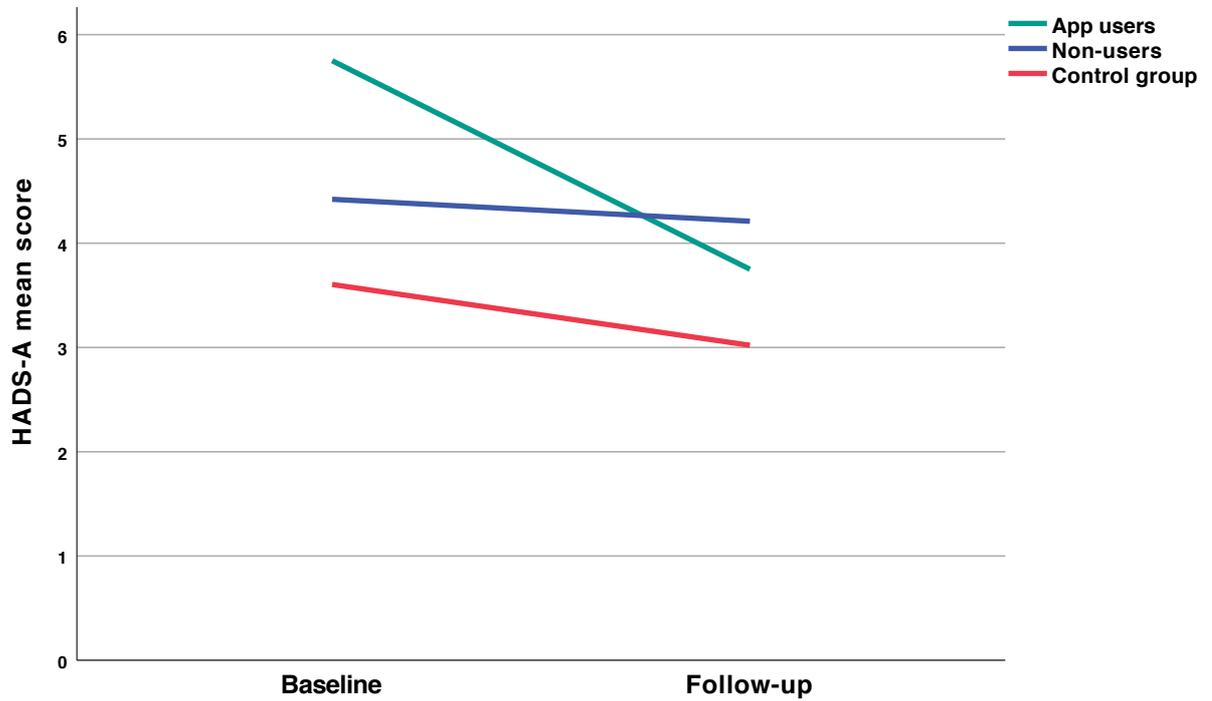


Figure 6. Differences in HADS-A mean scores from baseline to follow-up for control group and intervention group stratified by educational level. The reference line indicates the MCID.

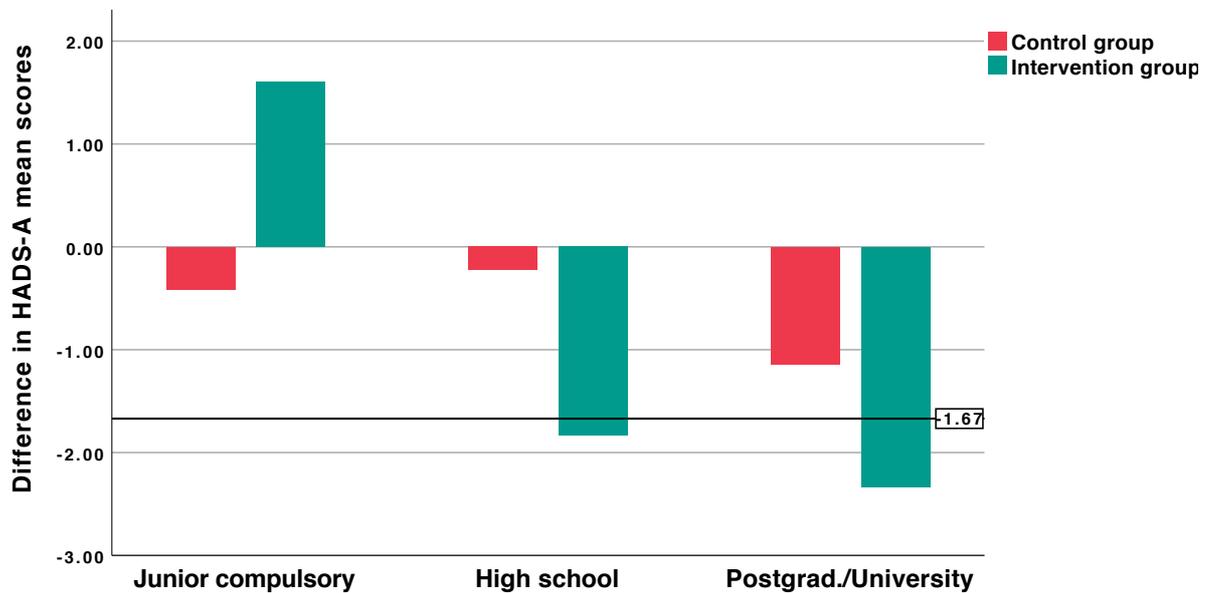
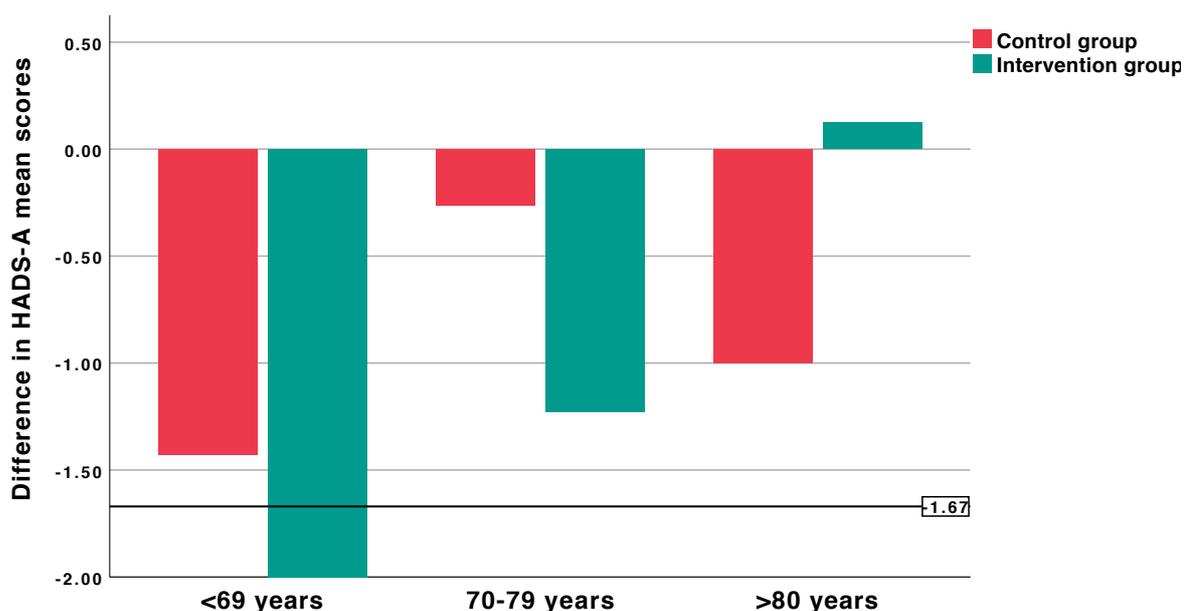


Figure 7. Differences in HADS-A mean scores from baseline to follow-up for control group and intervention group stratified by age. The reference line indicates the MCID.



A univariate linear regression model was used to assess the association between potential confounding variables and HADS-A mean scores. Potential confounding variables in these relationships were incorporated in a multivariate linear regression model including educational level, app usage and length of hospital stay. The selection of variables was based on measured variables with a known or suspected relevant effect on anxiety, or exhibiting $p < 0.10$ in the univariate analysis. In the multivariate linear regression, higher educational level and app usage were both associated with decreased anxiety mean scores, whereas length of hospital stay was associated with increased anxiety mean scores measured by HADS-A (Table 6).

Table 6. Factors associated with HADS-A mean scores in a uni- and multivariate linear regression model.

Factor	Regression coefficient (SE)	95% CI	P value
Univariate linear regression			
App usage	-1.552 (0.766)	-3.074, -0.030	0.046*
Educational level	-1.110 (0.448)	-2.000, -0.219	0.015*
Length of Hospital Stay	0.183 (0.063)	0.063, 0.304	0.003*
Randomization	-0.668 (0.688)	-2.034, 0.700	0.334
Age	0.083 (0.049)	-0.014, 0.180	0.092
Female sex	-1.244 (0.978)	-3.186, 0.699	0.207
Surgical treatment type (open vs EVAR)	-0.057 (0.695)	-1.439, 1.324	0.934
Multivariate linear regression			
App usage	-1.437 (0.725)	-2.878, 0.004	0.051
Educational level	-0.938 (0.429)	-1.791, -0.086	0.031*
Length of Hospital Stay	0.183 (0.061)	0.063, 0.304	0.003*

SE = Standard Error. CI = Confidence interval.

5.5.3 Effects on depression and health-related quality of life

No significant differences in HADS-D mean scores were found between the control and intervention group. In the tertiary analyses of surgical treatment method, sex or use of the eHealth tool, no significant findings were detected. The physical component summary (PCS) score of the SF-12 instrument was similar between the intervention group and the control group at both baseline and postoperative follow-up. Both treatment groups decreased in physical functioning following surgical repair. Among the subgroup of patients in the intervention group who used the eHealth tool and received psychosocial support, the decrease in PCS was more pronounced than in the control group (4.32 vs -1.16, $p=0.042$). No differences were detected between the groups regarding the mental component summary score (MCS) at baseline or postoperatively.

5.6 PARTICIPANTS' EXPERIENCES OF THE EHEALTH INTERVENTION

Patients' experiences of the eHealth tool and psychosocial support were explored through individual, in-depth interviews. Their attitude to and familiarity with modern technology guided their decision to utilize the eHealth tool, irrespective of the perceived ease-of-use of the tool. In the decision to use the eHealth tool or other information sources, they were largely guided by their long-term information-seeking behavior. The eHealth tool gave a sense of relief by alleviating patients' responsibility for informing next of kin.

The analysis revealed that participants at times were influenced by factors outside the intervention study, such as their mental state. They described being unable to assimilate new methods for learning when entering the study, approaching surgical treatment, and warranted access to the eHealth tool earlier during the care trajectory.

The interpersonal relationship with the health care staff was crucial to participants' ability to submit themselves and rely on the competence of the staff. When this relationship was harmed or disrupted, anxiety arose. As the intervention was designed as an add-on to standard care, encounters with health care staff outside the intervention largely affected their experience of the care trajectory.

6 DISCUSSION

6.1 DISCUSSION OF FINDINGS

6.1.1 Understanding patients' learning needs

The importance of receiving adequate and timely information prior to surgery is clarified by the results of this thesis. It also highlights the importance of having access to information after discharge. The Through the Patients' Act (2014:821), adopted by the Swedish Parliament in 2015, the position of the patient is strengthened by the promotion of self-determination and participation. The responsibility for ensuring that patients have been adequately informed lies heavily on the care giver, and the starting point for this process is understanding the needs of the patient. Although the learning needs of AAA patients were explored and described in **paper I**, participants in **paper IV** described that they at times were overwhelmed by the amount of preoperative information delivered just before surgery. This signifies the importance of tailoring the care to patients' needs, and that failure to adjust and follow up information can have adverse effects on patients' wellbeing, such as increased anxiety and detained participation.

6.1.2 Adjusting information to patients' needs

Whether patients acquire information individually or through face-to-face conversations, their capacity to learn and assimilate information is affected by a number of factors, some of which are specified in this thesis. Patients' needs in learning situations do not only pertain to the content of the information, but also the timing, environment and ways in which information is delivered. In face-to-face conversations with health care staff, participants described mediating the conversations to match their own learning needs. In these situations, health care staff most often responded to these signals and adjusted the information to the needs of the patient. The process where patients are active participators in learning situations, guided by previous experience, motivation and commitment, can be understood through andragogy, adult learning theory. (37) According to andragogy, a nonhierarchical relationship between health care staff and the patient, where the patient is trusted and respected, facilitates the learning process. This entails engaging the patient in the learning situation. Patient engagement, or patient participation, inherently affects their ability to search for and manage information, whether online or in face-to-face encounters. (144) In this sense, patients' needs may not always be articulated but can be understood by how they are expressed, as patients' information-seeking behaviors. (145) This correlates to our findings, where patients described actively seeking information online when the health care failed to adequately meet their learning needs, and in some cases evading information when this was justified. Health care professionals' ability to acknowledge patients' information seeking behaviors has been identified as a key factor to patient engagement and satisfaction. (144) In situations where the health care staff was perceived as stressed or overstrained, patients suppressed their learning needs and refrained from raising questions or concerns. Through our results, only patients'

perceptions of health care professionals' ability to adjust information to patients' learning needs are described. Health care professionals' perspective on preoperative information for AAA patients may deepen the understanding of the interactions between patients and health care staff in learning situations.

A recurring theme throughout this thesis is the significance of timing information to patients' needs. More specifically, patients expressed unmet learning needs during the surveillance period, which rendered them unprepared for surgical treatment. One anticipated advantage of the eHealth tool was the possibility for participants to use the tool at different timepoints and in environments where they felt safe and calm, and return to the eHealth tool for specific information as they wished. In the intervention study, the eHealth tool was administered to participants in the intervention group a week prior to surgery. This time point was chosen to incorporate the intervention into the clinical routine at the department where the study was carried out. However, participants described being insusceptible to receive information at this point and warranted information earlier in the care trajectory, during the surveillance period. In a systematic review of the literature, timing did not significantly influence preoperative anxiety, pain or length of stay. (146) Through our results, inferences regarding the effect of timing on preoperative anxiety cannot be drawn. Albeit, timing of information is a recurring theme in the qualitative evaluations and seems to be an important factor to AAA patients' ability to assimilate information prior to surgery. The results of this thesis highlight the complexity of delivering information, and signifies that there is no universal solution to the content, level and timing of information to minimize the psychological distress that information might impose. Individualization and increased accessibility are vital aspects and can partly be attained through eHealth solutions. An enhanced understanding of the factors affecting patients' psychological health during the care trajectory of AAA repair may yield indispensable amendments to the routines for delivering preoperative information.

6.1.3 The usefulness and relevance of eHealth tools in a surgical setting

The results of the intervention study indicated that an eHealth tool combined with psychosocial support had a positive effect on anxiety mean scores, measured with HADS-A, when comparing to standard care. Through the development of the eHealth tool, feasibility for use of the eHealth tool in a setting of AAA patients was only partly attained. Within the intervention group, only half of those who were offered the eHealth tool chose to utilize it. Non-users of the eHealth tool, receiving standard care with additional psychosocial support, had a smaller reduction in HADS-A mean scores compared to users of the eHealth tool. In a systematic review, the use of eHealth programs targeting patients with different cardiovascular diseases was 36% to 97%, which is in line with our findings. (147) The proportion of participants who chose to use the eHealth tool can therefore be assumed to reflect the acceptance level in a clinical setting of AAA patients.

6.1.3.1 Factors affecting the acceptance and use of eHealth

The acceptance of technology can be influenced and increased by addressing barriers to eHealth use. Known predictors of technology acceptance are perceived usefulness, social influences and attitude. (148) The eHealth tool used in our study had a fairly simple design, with limited interactivity and individualization. This may have affected the perceived usefulness and relevance of the eHealth tool from the patient's perspective. Patients who declined to use the tool did so prior to having been presented with the eHealth tool, indicating that their decision may rather have pertained to attitude and familiarity with modern technology. This was also described in the qualitative evaluations, where non-users described lacking interest or confidence in using modern technology. The participatory design (PD) methodology adopted during the development of the eHealth tool has been deemed suitable for the engagement of older patients in design processes. (87) Although potential end-users were involved in the development, the final version of the tool was confined by technical and financial limitations. Nevertheless, the simple interphase and large buttons of the eHealth tool were designed to appeal to older adults and was validated by potential end-users during the development of the tool. In the qualitative evaluation, economic constraint was described as a limiting factor to the use of modern technology. When presented with the eHealth tool, participants were offered to lease a tablet free of charge but few chose to do so. This may be explained by their unfamiliarity with this type of technology at large, rather than lacking access to a smart phone.

Poor health literacy is known to negatively affect the acceptance and use of eHealth services. (77) Knowledge of the health literacy of a patient population is important when developing educational material in general, but also in the design of eHealth services. In patients with arterial vascular disease, limited health literacy skills amount to 76.7% in a Dutch cohort study. (73) Age and educational level are independently associated with poor health literacy, where older patients with low educational level present with lower health literacy. (73) Although health literacy was not assessed in our cohort, non-users of the eHealth tool were older and had lower educational level. Although health literacy entails unique sets and skills, it has been shown to be a mediator between educational level and self-reported health status. (149) Our findings relating to educational level may therefore partly be understood as poor health literacy. Initiatives to improve the acceptance of eHealth among older patients with low educational level may prove useful in this context.

6.1.4 Anxiety, depression and health-related quality of life

6.1.4.1 Understanding preoperative anxiety

Anxiety is a common condition among older adults. (150) Anxiety is often rather stationary, but can also be affected by an altering life event such as a diagnosis or medical treatment. (150) In our cohort, 19% reported HADS-A scores of >8 at baseline, which is in line with previous studies. In a cross-sectional cohort study of geriatric patients, 17% presented with

clinically significant anxiety, defined as HADS-A >11, at hospital admission. (151) Previous studies have reported various anxiety levels at diagnosis, during surveillance and through surgical treatment, depending on instruments used, timing of measurement and length of follow-up. (113, 115) In patients scheduled for AAA repair, 29% have been found to suffer from borderline or clinically significant anxiety. (121) Following surgery, anxiety levels naturally decrease. (152) To determine the effect of an intervention on anxiety, the natural course of anxiety needs to be differentiated from levels mediated by the intervention. In the intervention study, the effect of the intervention was assessed by the minimal clinically important difference (MCID), which has been set at 1.29-1.67 for cardiovascular patients. (139, 140) HADS-A mean scores reported by the control group represent the natural course of anxiety during the surgical care trajectory, whereas the effect of the intervention is understood by differences within and between treatment groups. The mean reduction in HADS-A for participants utilizing the eHealth tool and receiving psychosocial support exceeded this threshold, which points to a clinically important reduction in anxiety.

The effect of anxiety of cognitive function is well-established, such that anxiety significantly impairs working memory. (153) Hence, the high prevalence of anxiety symptoms in patients facing AAA repair may affect their ability to comprehend and assimilate information. In encounters with anxious patients, the preoperative information should be adjusted accordingly. In the qualitative evaluation, patients described that anxiety was evoked in encounters with health care staff, for example when risk information was delivered. Although they appreciated being fully informed, they described responding to these situations with detachment and disengagement. Balancing the risk of overinforming anxious patients and underinforming patients with extensive learning needs is a challenging task. A key factor in adjusting information to the anxiety levels of patients is to correctly identify those suffering from anxiety. Preoperative anxiety is more pronounced in certain groups. In a cross-sectional study of 127 patients waiting for cardiac surgery, the analysis revealed two clusters of patients, one of which had significantly higher anxiety levels. (154) Factors associated with high anxiety levels were negative illness perception, larger need of information, older age and female sex. (154) Educational level and female sex have been identified as attributing factors to preoperative anxiety in other studies. (155, 156) In the intervention study, female participants reported higher anxiety mean scores than men at baseline. A larger proportion was also planned for open surgical treatment, which may explain this variation. Further inferences regarding the association between sex and anxiety in this cohort would require a larger sample.

Preoperative anxiety has shown to be associated with negative outcomes such as increased mortality and morbidity in patients undergoing cardiac surgery. (120) A randomized, controlled trial found that a nurse-initiated preoperative education intervention reduced anxiety symptoms and complication rates in cardiac patients. (157) In the multivariate linear regression of **study III**, length of hospital stay was associated with higher anxiety mean scores, indicating that a prolonged or obstructed recovery period induces anxiety. However, this finding may refer to the increased perioperative risk associated with open AAA repair.

Thereby, the causal relationship of this association cannot be determined through our results. In a study examining psychiatric complications following open surgical repair of AAA, a striking 32% of patients presented with objectively determined postoperative psychiatric morbidity two years following surgery. (158) Hence, both preoperative anxiety and postoperative psychiatric morbidity are common in patients undergoing surgery. Although anxiety and depressive symptoms are associated with poor functional outcomes following cardiac surgery (120), the long-term effects of psychological distress in AAA surgery are not fully understood.

6.1.4.2 Depression and HRQoL during AAA repair

In our study, 12% had diagnosed or medically treated depression at baseline medical chart reviews. According to the self-reported depressive symptoms measured by HADS-D at baseline, this prevalence was 10%, indicating that the instrument accurately captures depressive symptoms in this cohort. This prevalence also reflects reported levels in population-based samples of older adults. (159) The association between depression and AAA development has gained attention in recent years, but the effect of depression on the surgical care trajectory is yet to be explored. (160)

In a randomized study of Swedish older adults stratified by age, the SF-12 summary scores PCS and MCS decreased significantly with higher age. (135) In the group aging from 75 to 79 years old, a PCS mean score of 41.6 and MCS mean score of 52.1 was noted. (135) In our sample, the PCS mean score at baseline was slightly higher, 47.3, and MCS lower than these values, 51.0. This may reflect the nature of AAA disease, an asymptomatic condition which mainly affects mental rather than physical aspects of patients' health. Several recent studies have reported lower HRQoL levels in AAA patients compared to the general, age-matched population. (115, 161) This was not reflected in our findings. In our cohort, PCS dropped postoperatively in both the control and intervention group. This may pertain to the physical trails of surgery, which may still be distinct one month following surgery. The slight increase in MCS can be explained by the postoperative relief which was described by patients in the qualitative evaluation. No significant differences were found between the control and intervention group, indicating that these parameters were not affected by the eHealth intervention.

6.1.5 The association between educational level, readability and anxiety

Through this thesis, the learning needs of patients with abdominal aortic aneurysm were described, and an eHealth tool was developed with contents aiming to satisfy these needs. When testing the eHealth tool and psychosocial support in a clinical setting, striking differences were seen regarding the effect on anxiety in patients of different educational levels. In the intervention group, patients at postgraduate or university level had a reduction

in HADS-A mean scores of -2.33 from baseline to follow-up, whereas the corresponding difference in patients who had completed junior compulsory school had an increase in HADS-A mean scores of 1.6. During **studies I and II**, the educational level of the participants was not noted, and it is therefore possible that the patients who were engaged in the development of the eHealth tool were not sufficiently distributed across different educational levels. Furthermore, the readability analysis in **paper II** revealed that the content of the eHealth tool corresponded to grade 10. To acknowledge the poor health literacy previously addressed, patient education materials are recommended to be written on a fifth to sixth-grade level. (162) In a study of currently available online information about AAA, a median FRES of 39 was noted, corresponding to college readability levels. (62) In another recent, comprehensive readability analysis of online AAA information, the overall mean reading grade level was 12.8, around the level of a high school senior. (61) The adverse effect in the group of patients with a low educational level may pertain to the high language level in the eHealth tool. Adjusting the language of patient education materials to the readability level of the readers often proves to be a balancing act between the preferences of health care staff, patients and their next of kin. During the development of the eHealth tool, care was taken to ensure that essential information was retained while the readability was addressed. In **paper IV**, participants described being overwhelmed by the amount of preoperative information but negative perceptions of the content and language level were not reflected upon. The potential negative effects of insufficient readability of patient education material in this cohort are thereby not fully understood.

6.1.6 Psychosocial support

The psychosocial support provided in the intervention was not assessed separately. However, due to the fairly large proportion of participants who did not utilize the eHealth tool, the effect of psychosocial support can be understood as the difference in anxiety mean scores between the control group and non-users of the eHealth tool in the intervention group. These results indicate that psychosocial support through a patient-centered approach did not solely affect preoperative anxiety in this patient cohort. However, the timing and structure of the psychosocial support sessions may not have adequately corresponded to the needs of the patients. The partnership between patient and caregiver is at the very core of PCC. To establish and strengthen this partnership throughout the care trajectory, the efficacy of psychosocial support may have been favored by an earlier introduction.

It is also possible that the potential effect of psychosocial support was not adequately captured by the chosen instruments. In a study of a person-centered intervention of psychosocial support combined with an eHealth tool for patients with acute coronary syndrome, the intervention had a positive effect on patients' perceived self-efficacy. (163) Psychosocial support by PCC has also been linked to improved patient engagement and clinical outcomes in cardiac patients. (164) In our study, participants described that the psychosocial support added to their sense of being cared for and was perceived as

meaningful. Although no statistical significance was noted between the treatment groups, participants' perceived value of the psychosocial support was emphasized in the individual interviews.

6.1.7 Vulnerable groups

The eHealth literacy of potential subjects invited to participate may have caused selection bias in all phases of the development and testing of the eHealth tool. It is plausible that patients with experience or self-confidence in using modern technology are more prone to participate in eHealth research and development. In **study I** and **II**, usability and acceptability aspects may therefore not have been adequately captured in groups with less experience of modern technology. In **study III**, participants utilizing the eHealth tool were younger and more well-educated than the non-users. This limits the transferability of the results to older patients with lower educational level, a group already at risk of being left behind in the digitalization of health care services. (90)

A learning process is affected by several factors such as the dynamics and hierarchy of conversations in a hospital setting, as well as the access and assimilation of information. (38) Through the current studies, it is difficult to establish which of these factors that obstruct or enhance patients' learning. Gender is known to be associated with varying information-seeking behavior, with women expressing greater information needs. In a study of breast cancer patients' information needs, those with low health literacy reported a significantly higher degree of unmet information needs at baseline and during the course of cancer treatment. (165)

These results highlight the importance of adjusting the information and discharge planning in accordance with the health status, sex, cohabitation and educational level of patients. If and when psychosocial support cannot be provided to all patients, vulnerable patient groups should therefore be prioritized. In **paper IV**, participants expressed that they understood their need for psychosocial support in retrospect, rather than in the actual perioperative period. Therefore, the responsibility to adequately identify and target these needs earlier in the care trajectory lies heavily on the health care staff. In clinical encounters, health care staff should acknowledge that the need for psychosocial support or further information may not always be expressed by the patients who need it most.

6.2 METHODOLOGICAL CONSIDERATIONS

6.2.1 Research design considerations

In all fields of research, the chosen methods need to be challenged before the utility of findings can be assessed and conclusions proposed. While quantitative methods by randomized, controlled trials can establish correlations between exposure and outcome,

qualitative studies are needed to understand the underlying processes and explanations to these correlations, the *why*. There may be important confounding factors that are not captured by the instruments used for data collection in a quantitative study. In this case, qualitative methods produce a different kind of knowledge about the articulated and latent experience of an intervention. (166) Qualitative studies enrich the knowledge and understanding of a phenomenon but cannot point to which factor is of clinical significance, this would require an interventional study. Hence, the two methodologies, associated with the positivist and constructivist research paradigms work synergistically.

The term *triangulation* can be used to describe validation between different findings or the process of studying a phenomenon by different methods to gain a deeper and more complete understanding. (167) The latter, a methodological metaphor for drawing inferences from qualitative and quantitative findings, can be applied to the studies constituting this thesis. The different methods were chosen to widen the understanding of learning through eHealth from different empirical settings. The first three studies are interconnected such that each study provides input to the following study, also known as sequential mixed methods. In the third and fourth study, data collection partly concurred. (167)

6.2.2 Quantitative data

6.2.2.1 Design

The study design for the interventional study in **paper III**, a parallel group, randomized controlled trial, was chosen to generate robust evidence of the effect of the intervention. The most compelling way to establish a relationship between a treatment/exposure and outcome is through random allocation in a strict, double-blind manner. (168) At study initiation, permuted block technique with a block size of 10 was chosen to minimize spill-over between the treatment groups. Permuted blocks ultimately generate randomized, even strata where specific participant characteristics are evenly distributed between the treatment groups. In the intervention, this was not the result. Due to the decreased staffing and surgical capacity during the summer months, enrolment slowed down during these months. Several summers, this coincided with enrolment to a block of controls. As the clinic generally performs more EVAR and less severe cases during the summer, this caused a certain skewness in the distribution of comorbidity and surgical treatment between the groups. Due to the relatively small sample in this study, a block size of 10 to each treatment arm may have been too wide, causing these imbalances between the groups. Another limitation to large blocks is the researcher's ability to predict the randomization sequence. In our study, the researchers were not blinded to the randomization sequence. This implies a risk of researcher bias in the enrolment to the study. (168) In the intervention study, the extent to which the eHealth tool was utilized was tracked through a web-based software. As the long-term effects of the intervention will be assessed, these data are not summarized and presented in this thesis.

Furthermore, a health economic evaluation of the intervention may have provided valuable information regarding the applicability of the intervention into clinical practice.

6.2.2.2 *Type I and II errors*

In hypothesis testing, the aim is to clarify whether the observed effect is the result of chance, or a true difference between treatment groups. In evaluations of findings, there are two types of random errors. A type I error means that a false positive difference is observed, and that the null hypothesis is falsely rejected. In type II errors, a true difference is instead missed and the null hypothesis is falsely accepted to be true. To determine the risk of drawing inaccurate inferences in the form of a type I error, a level of significance is set. This level, in our study set to 5%, means that the probability of falsely rejecting the null hypothesis is 5%. Hence, a lower significance level decreases the risk of performing a type I error. If the wrong measure is chosen, it can cause a type II error, failing to detect a true effect. Other reasons for type II errors are underpowered studies, where the sample size is too small to detect a difference in a hypothesis test. In **paper III**, an estimate of the anticipated effect size was challenged by the small number of studies reporting on HADS among patients in vascular surgery. The power calculation was therefore based on two interventional studies of patients with acute coronary syndrome, with HADS as the primary outcome measure. (169, 170) In a study of 153 Chinese patients scheduled for cardiac surgery, an intervention consisting of an information leaflet and verbal advice by a registered nurse led to a decrease in HADS-A by -3.6 points in the intervention group compared to -0.7 points in the control group, receiving standard care. (170) The transferability of these findings can however be questioned. The context in which the study was conducted is essentially different, where the availability of educational material in Chinese is limited there are no legislative requirements regarding patient education or engagement in health care. (171) Therefore, the preoperative information can be assumed to be less ample than in a Swedish context. Secondly, the reported HADS-A mean scores at baseline in **paper III** were markedly lower than those observed in the reference study upon which the effect size was estimated. Furthermore, in the analyses, only half of the patients in the intervention group received the intended intervention, with both the eHealth tool and psychosocial support. As those receiving the full intervention were fairly few, the risk of a type II error cannot be ruled out.

6.2.2.3 *Validity*

Validity can be defined as the relevance of the collected data for the selected problem or phenomenon, and the ability of the instruments to accurately measure what is to be measured. *Internal validity* refers to the degree to which the observed effects were caused by the intervention or other extraneous factors not adequately controlled for. (166) One key aspect to internal validity is that the intervention was carried out correctly. The intervention was designed as an add-on to standard care. The psychosocial support sessions were not guided

by a specific protocol but rather depended on the individual needs expressed by the patients. The interpretation and management of these needs may have differed between the registered nurses that carried out this part of the intervention. These aspects were regularly discussed within the research group to maintain consistency in the psychosocial support provided to patients. One method to enhance the internal validity of an intervention is through double-blinding, but as described previously, this was not possible due to the nature of the intervention. Selection bias may also affect the internal validity of a study. By employing strict block randomization, this risk was minimized. Reasons for non-participation were only partly explored and described. Furthermore, reasons for non-completion and drop-out of enrolled participants could be described in further detail to enhance the internal validity of the study. Non-completion was more common in participants having undergone OR, which may pertain to the physical and mental strain that is associated with this treatment method in the early postoperative phase. Selection bias can also occur as a result of narrow inclusion criteria, or failure to enroll a certain share of the cohort. In our study, patients with little or no experience of modern technology may have been intimidated by the study and may therefore not be adequately represented in the results. Aside from this, inclusion criteria were wide, to allow for enrolment of a representative sample. One threat to the internal validity of a study is the possible impact of confounding factors on the result, which is generally considered to be a smaller problem in RCTs.

External validity refers to the degree to which the findings of a study can be transferred and valid for other settings or cohorts. Our cohort of AAA patients are demographically representative of AAA patients nationally and internationally. Although the findings pertain to AAA patients, they may also prove useful in other contexts of eHealth development and evaluation. Within the field of vascular surgery, patients with AAA are usually slightly younger at diagnosis. This may imply that they are more prone to utilize modern technology, and that our results therefore cannot be transferred to other patient groups with peripheral vascular disease. However, the outcomes are not specific to AAA care. The understanding of the course and nature of preoperative anxiety and the usefulness of eHealth and psychosocial support is possibly relevant and applicable in other settings of adult patients planned for surgical treatment. In vascular surgery, preoperative anxiety has hitherto been given little attention and further investigations are likely to yield valuable insights.

6.2.2.4 *Strengths and limitations to chosen instruments*

Even though the instruments used in this thesis had been frequently used and adequately validated, the inferences based on these instruments should be scrutinized. The process of determining the validity of a specific instrument entails several steps. Although the purpose may be to develop an instrument for use in a wide variety of contexts, the initial validation and psychometric evaluation most often provide information about the degree to which an instrument accurately measures a specific attribute in a specific context of patients or healthy

individuals. The transferability of the instrument to other contexts or cohorts are then assessed by researchers in the planning of a clinical trial.

Patient reported outcome measures (PROMs) are widely used in vascular surgery, and once they are validated for use in a specific patient group or context, they are rarely questioned or reassessed. (172) The aim and purpose of a study should always guide the decision of instruments and methods for data collection. If the aim is to evaluate an intervention or to know more about patients' perspective on a care trajectory, qualitative methods could be used in both cases. If quantitative instruments such as questionnaires are chosen, a clear understanding of the main focus and its demarcation to adjacent concepts is needed. There may be other important factors that better explain the processes that affect patients physical and psychological wellbeing during the care trajectory of AAA repair that were not adequately captured through the chosen instruments.

HADS is commonly used to evaluate symptoms of anxiety and depression in somatic patients. (122) Although it is not validated for diagnostic use, it provides accurate estimates of the severity of symptoms and their clinical implications. (123) It is also validated for use in the older population, a cohort where physical ailments may affect psychological wellbeing. (133, 151) Furthermore, it is well established in AAA research, both in evaluations of population-based screening, the surveillance period and surgical treatment. (112, 113) It's major contribution to the understanding of patients' psychological wellbeing during AAA treatment however lies in the capability of the instrument to capture the minimal clinically important difference (MCID) in clinical interventions. This MCID functions as an indicator of treatment success in clinical interventions, and extends the meaningfulness of interventions beyond statistical significance to clinical implications. The MCID used in **paper III** was based on cardiovascular patients with corresponding demographic and comorbidity characteristics as the AAA patients in our study cohort. (139)

The SF-12 is a validated instrument, measuring physical and mental aspects of HRQoL. It is a compressed version of the widely used SF-36 instrument, and has adequate product-moment correlations across its twelve items when comparing to SF-36. (119) However, the dimensionality and factor structure of the instrument has been challenged in several thorough evaluations. (134, 135) For this reason, only the summary scores (PCS and MCS) were included in the analysis of **paper III** and analyses of the inherent eight items of the instrument were not performed. The disease-specific aspects of AAA, an asymptomatic but potentially lethal condition, may not be adequately captured by the instruments used in the current thesis. A validated HRQoL instrument with adequate sensitivity and specificity in capturing aspects of physical and mental health among AAA patients may prove useful in this context.

Readability parameters of the eHealth tool were assessed using the Flesch-Kincaid Reading Ease score (FRES) and Flesch-Kincaid Grade Level (FKGL). These formulas produce scores by mathematical calculations based on parameters such as words per sentence, mean word length, and number of syllables per word. (173) There are numerous formulas to assess

readability, such as Fry and Simple Measure of Gobbledygook, and the Flesch-Kincaid formulas correlate highly with these instruments. (131) However, aside from being readable, patient education material should also be comprehensible, relevant and applicable to patients. Comprehension depends on various factors such as layout, motivation, prior knowledge and literacy skills of the recipient. (131) These aspects were not captured by the chosen instruments, and inferences therefore cannot be drawn regarding the comprehension of the contents of the eHealth tool in our cohort of patients. Furthermore, the FRES and FKGL readability formulas are based on an American standard, which may not transfer accurately to the Swedish population. (174) The LIX formula is an instrument designed to evaluate readability of texts in Swedish. (175) It has however been criticized for its superficial metrics and is not commonly used to assess medical text, which would limit the transferability of our findings. In this thesis, FRE and FKGL was therefore chosen for the readability analyses.

6.2.3 Qualitative data

While quantitative research follows a structured, inherent design with distinct measurement methods, naturalistic inquiry using qualitative methods are less settled. The research aim and design can be altered and reassessed during data collection and analysis. In qualitative research, the concepts of reliability and validity are often referred to as trustworthiness. (176) Lincoln and Guba proposed a framework of criteria for the assessment of trustworthiness in qualitative studies. (177) The methodological discussion regarding the qualitative parts of the thesis will follow this framework under the following headings: credibility, dependability, confirmability and transferability.

In qualitative inquiry, *credibility* implies confidence in truth of the data and its interpretations. (96) To attain credibility, all aspects of data collection, handling and analysis need to be tested. In the collection of interview data, the credibility is dependent on how the interviews were carried out. The members of the research team, participating in the FGIs and performing the individual, in-depth interviews, had preconceptions of the care trajectory of AAA from years of clinical experience caring for these patients. While an interview guide can constrain interviewers from indulging in his or her preconceptions, it can also introduce bias as the questions may lead respondents into reasonings that they would not have commenced in a narrative interview. The interview guides used in the different studies were cautiously reviewed within the research team to correspond to the study aims, while at the same time minimizing researcher bias. All interviews also included open questions, enabling the participants to elaborate freely on their experiences and viewpoints. Another factor attributing to the credibility of a study is the sampling method used during study enrolment. In **paper I**, all patients who fulfilled the inclusion criteria were asked to participate but the enrolment period was protracted by the difficulty in gathering patients for the focus group interviews. Those who were still working found it difficult to find the time to participate, which contributed to a higher mean age compared to the other studies in this thesis. This factor may form a threat to the credibility of the study in reflecting the true, real-world

setting. Also, the median time from surgery to the interview was longer, which may have affected the participants' ability to recall specific details of their care. In the interpretation of results, credibility involves the degree to which the themes and categories convey the data. (178) In this sense, credibility is achieved by maintaining closeness to the original text and moving back and forth between the meaning units, codes and categories throughout the analysis until consensus is reached within the research group.

Dependability relates to the stability of data over time and contexts, resembling reliability in quantitative studies. When the data collection extends over time, there is a risk of inconsistency in the data collection. (178) The data collection in this thesis stretched over several years, during which the technological advancements rocketed and the familiarity and use of modern technology among older persons was rapidly evolving. This may have affected the dependability both within and between the different papers. However, no major alterations were made to the clinical routines or surgical techniques at the department. The context was therefore largely stable over time.

For qualitative data, *confirmability* refers to the accuracy of interpretations and the researcher's ability to reflect on researcher bias. In naturalistic inquiry, the epistemological approach of the researcher is pivotal to the confirmability of the findings. One way of enhancing the confirmability of findings is through parallel content analysis, with discussions and confirmations of findings within the research group. In focus group interviews, interpretations can be also be discussed and descriptions verified or rejected by the other focus group members during the interview. (127) This is a strength to focus group methodology, as the verification and confirmation of findings can take place during the course of data collection. In individual interviews, confirmability can be attained through member checks, meaning that the respondents review the interpretation of findings during the analysis process. In **paper IV**, the absence of member checks is a limitation to the confirmability of the findings.

Transferability can be described as "the extent to which the findings can be transferred to other settings or groups". (138) Although authors can propose areas to which a study may be relevant, the transferability of a qualitative study to other context is best assessed by the reader. By providing a clear description of the setting, context and selection of participants, transferability is facilitated. In the current thesis, the sample in the interview studies was fairly small and drawn from a single center. These aspects could negatively affect the transferability of the findings to other settings. However, the context and participant characteristics are described in detail, forming a basis for the assessment of the transferability to other settings.

7 CONCLUSIONS

The results presented in this thesis add to the understanding of AAA patients' learning needs, and factors that hinder or stimulate learning in the trajectory of surgical treatment. The four papers highlight the complexity of tailoring information to the needs of the patients, and point to the importance of adjusting the timing and content while acknowledging patients' mental state.

- An eHealth intervention can be safely and effectively implemented in a clinical setting.
- An eHealth tool paired with psychosocial support reduces anxiety in patients undergoing surgical treatment of AAA.
- Psychosocial support should be introduced earlier in the surveillance period, and maintained throughout the care trajectory.
- Special attention should be paid to vulnerable groups such as older patients and those with low educational level, to increase their acceptance and use of eHealth.
- A large proportion of AAA patients undergoing surgical treatment present with anxiety symptoms.
- Patients' attitude to modern technology is vital to the utilization of eHealth, and should be respected.
- The readability of patient education material remains a challenge, and should be assessed in regard to the literacy levels of the targeted cohort.

8 FUTURE PERSPECTIVES

This thesis forms a basis onto which eHealth initiatives can be designed and implemented. It has also generated new questions and ideas to improve the care of AAA patients:

- How can eHealth and psychosocial support be implemented in AAA surveillance programs, and what are the potential effects?
- What are the needs of next of kin, and how can adequate information and support be provided to them?
- What are the long-term effects of an eHealth intervention on patient-reported outcome measures and clinical outcomes?
- What effect does health literacy and socioeconomic positioning have on psychological distress, morbidity and mortality in AAA patients?
- How does anxiety affect learning, participation and clinical outcomes in patients undergoing different types of vascular procedures?

The effects, acceptance and perceptions of eHealth has implications that extend beyond AAA, and can provide valuable insights into the development of eHealth solutions targeting other patient cohorts within a broader surgical field.

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