

Delayed and cancelled orthopaedic surgery: Causes and consequences

Ulla Caesar

Department of Orthopaedics, Institute of Clinical Sciences,
Sahlgrenska Academy, University of Gothenburg,
Gothenburg, Sweden, 2019



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ulla.caesar@gu.se

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Correspondence: ulla.caesar@gu.se

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“It always seems impossible
until it's done.”

Nelson Mandela

Abstract

Introduction: Extended waiting times, over-booked waiting lists and cancelled and delayed surgical procedures are realities for some patients treated at orthopaedic clinics in Sweden. This situation affects the prioritisation procedures for both emergency and elective surgery and results in even longer waiting lists, not only for planned patients but also for emergencies. Cancellations and delays are reported to be common and it is therefore important to study how to prevent them and also to understand how cancellations and delays are experienced by patients.

Method: Studies I and III were retrospective, observational, single-centre studies with data collected from the hospital's registers. The aim was to evaluate and describe the number of and reasons for delays and cancellations, as well as waiting times. Study I comprised 17,625 elective patients over a period of five years, while Study III comprised 36,017 emergency patients over seven years. Study II was qualitative and the aim was to elucidate the meaning of the lived experiences of patients after having hip or knee replacement surgery cancelled. The interviews were interpreted in three steps using a phenomenological hermeneutic analysis, which consists of a lifeworld perspective. In Study IV, the objective was systematically to search and review the literature for evidence of factors that

might be used to reduce cancellations of and delays to orthopaedic procedures. This study was conducted following the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines, the Cochrane Handbook and the SBU handbook (Swedish Agency for Health Technology Assessment and Assessment of Social Services). The Grading of Recommendations Assessment, Development and Evaluation (GRADE) was used to assess the quality of evidence in the included studies.

Results: In Study I, 6,911 (39%) of the 17,625 patients received at least one and some several cancellations. The most common reasons for cancellations were various patient-related factors 3,293 (33%). Cancellations due to treatment-guarantee legislation reached 2,885 (29%) and 1,181 (12%) of the cancellations were related to the incomplete pre-operative preparation of the patients. Organisational reasons were responsible for 869 (9%) of the cancellations. The median waiting time for those cancelled once was 54 days. In Study III, it was shown that 8,474 (24%) of the 36,017 patients scheduled for emergency surgeries were delayed and rescheduled at least once, some several times. Eighty one per cent of these delays were due to organisational reasons. Twenty-one per cent of all delays were re-scheduled within 24 hours, while

41% waited for more than 24 hours; some up to three days. In Study II, the findings were divided into four themes: (1) ending up in a conflict between two realities, (2) being exposed to an injustice and its unpleasant consequences, (3) being a pawn in a game and (4) being surprised by one's reactions and feelings. The comprehensive analyses revealed that the participants described their feelings as not being the chosen one and thereby feeling rejected. The participants described the cancellation using words and metaphors with connotations to physical pain, like feeling hurt. Moreover, the relationship between the participant and the healthcare provider was damaged by the cancellation. In Study IV, eight articles were included. The result of the analysis indicated that the evidence was ranked from low to very low across the different studies. The main limiting factor, which was the reason for a decrease in quality in some outcomes, was the study designs being non-randomised control (NRC) and a retrospective approach.

Conclusion: In Study I, more than a third of the patients had their surgery cancelled and, in Study III, almost a quarter had their emergency surgery re-scheduled. It appears that it should be possible to eliminate many of these cancellations, while others are unavoidable or caused by factors outside the responsibility of the clinic. One possible way of influencing the high rate of the elective patients' cancellations especially related to patients'

own requirements might be to involve them to a greater extent in the overall planning of the care process. In Study III, the majority, i.e. 81%, of the delays were related to organisational reasons. The results can be interpreted in two ways; first, organisational reasons are avoidable and the potential for improvement is great and, secondly and most importantly, the delays negatively affect patient outcomes. The result in Study II might be interpreted as a promising first step towards building a better understanding of patients' lived experiences of having a surgical procedure cancelled. Based on the evidence from this study, the present clinic and the Swedish healthcare administration of planning and scheduling orthopaedic surgery have potential opportunities to reflect on, develop and improve care. Study IV also revealed some items that might be useful to help reduce the risk of cancelled and delayed orthopaedic procedures. They include a fast-track pathway, improved preoperative guidelines and telephone contact with patients prior to surgery, as well as careful consideration of additional preoperative tests.

Keywords:

Appointments and schedules, Operating rooms/organisation and administration, Waiting lists, Cancellation, Orthopaedic surgery, Delayed surgery, Cancelled surgery, Perioperative nursing, Phenomenology, Hermeneutics, Qualitative method, Social rejection, Shame

Sammanfattning på svenska

Ortopediska operationer, som oväntat avbokas eller fördröjs har negativa effekter på var kliniks/sjukhus organisation och administration, på kostnader för samhället, för hälso- och sjukvården och inte minst för den enskilde patienten. Avbokningar eller fördröjningar drabbar patienten såväl fysiskt, psykiskt som socialt. Eftersom av- och ombokningar eller fördröjning av operationer är vanligt förekommande är det angeläget att beskriva antalet, den sammanlagda väntetiden och orsakerna till dem. Det är också angeläget att belysa hur de som blivit avbokade upplever situationen. Dessutom är det angeläget att sammanställa den vetenskapliga information som beskriver metoder, som skulle kunna användas för att förhindra av- och ombokningar.

Övergripande syfte med avhandlingen var således att beskriva antal och orsaker till avbokningar och fördröjningar av ortopediska operationer och belysa patienters erfarenhet vid en klinik som utför både akuta och planerade ingrepp, samt att beräkna den sammanlagda väntetiden för patienten.

Studie I och III är retrospektiva observationsstudier. Syfte med studie I var att beskriva orsaker till varför patienter som varit uppsatta för planerade ortopediska operationer avbokades och att beräkna den totala väntetiden fram till dess att operationen slutligen genomfördes.

Syftet med Studie III var att beskriva orsaker till fördröjningen av akuta operationer och att beräkna hur länge patienterna fick vänta på sitt ingrepp.

Metoden bestod av datainsamling från sjukhusregister och journaler under fem (I) respektive sju (III) år.

Studie I visade att av de 17 625 patienter, som hade bokats för en planerad operation under åren 2007–2011, avbokades 6 911 (39%) minst en gång och vissa flera gånger. Trettiofyra procent (3 293/9 836) av alla avbokningar skedde på patientens egen begäran, i första hand för att opereras vid ett senare tillfälle. Tio procent (671/6 911) avbokades mindre än 24 timmar före den planerade operationen. I genomsnitt fick patienterna vänta på en ny operation mellan 54 dagar för de som hade avbokats en gång och 96 dagar för de som hade avbokats fyra gånger. I Studie I framkom också att många patienter (29%) skickades till andra kliniker för att bli opererade. Orsaken till detta var framförallt vårdgarantin, dvs att på den aktuella kliniken var det inte möjligt behandla patienten inom 90 dagar.

Studie III visade att 24% (8 474) av de 36 017 patienter som under åren 2007–2013 inbokats för en akut operation, försenades och/eller ombokades minst en gång, några flera gånger. Åttio en procent av dessa förseningar berodde på organisatoriska

orsaker, vanligast var att en annan oplanerad operation prioriterades som mer akut. Tjugofem procent av de patienter som ombokades opererades inom 24 timmar, medan 41% väntade mellan 24 timmar och 3 dagar. Flera patienter med frakturer väntade mer än en vecka i hemmet på att bli uppsatta på operationsprogrammet på klinikkens operationsavdelning. De flesta i denna grupp hade en handleds- eller fotledsfraktur.

Studie II har en kvalitativ design med syfte att belysa patienters erfarenheter av att deras planerade höft- eller knäledsprotosoperation avbokades. Datainsamling skedde med djupintervjuer och analyserades med fenomenologisk hermeneutisk metod.

Resultat visade fyra teman: (1) Att hamna i en konflikt mellan två olika verkligheter, (2) att utsättas för orättvisa och dess negativa konsekvenser, (3) att vara en bricka i ett spel, där kliniken kan flytta runt spelbrickan efter behov och (4) att bli överraskad av de egna reaktionerna och känslorna.

Vidare kände deltagarna sig bortvalda och avisade, vilket är en av människans starkaste känslor, och härstammar från tiden då ett uteslutande ur en flock i stor utsträckning innebar döden. När deltagarna beskrev avbokningen användes ord, som var i överensstämmelse med uttryck för fysisk smärta, som att det verkligen gjorde ont ("att sitta fast i en rävsax", "att få en kokosnöt i huvudet") och att känna

sig sårad. Dessutom blev vårdrelationen mellan sjukhuspersonalen och patienten skadad av avbokningen. Studiedeltagarna önskade mer och bättre information om varför avbokningen skett. Då informationen var ofullständig hade de svårt att förstå situationen.

Studie IV är en systematisk litteraturöversikt, som genomfördes enligt rapporteringspunkterna för PRISMA och Cochrane Handbok for Systematic Reviews of Interventions. Syftet var att systematiskt söka och granska den vetenskapliga litteraturen efter åtgärder som är möjliga för att minska avbokningar och förseningar vid ortopediska ingrepp.

Studier som rapporterade avbokningar eller förseningar av akuta ortopediska och/eller planerade operationer och som jämförde olika interventioner mot traditionell vård ingick. The Grading of Recommendations Assessment, Development and Evaluation (GRADE) användes för att bedöma bevisvärdet av de inkluderade studierna.

Efter genomgång kvarstod åtta studier som inkluderades i analysen; samtliga var observationsstudier. Bevisvärdet på de ingående studierna rangordnades från lågt till mycket lågt. Även om studiernas sammanlagda kvalitet var begränsad, innehöll flera av dessa interventioner med signifikanta resultat, som potentiellt skulle kunna reducera väntetiden till operation, minska risken för avbokningar och fördröjningar.

List of papers

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- I Caesar U, Karlsson J, Olsson LE, Samuelsson K, Hansson-Olofsson E: *Incidence and root causes of cancellations for elective orthopaedic procedures: a single centre experience of 17,625 consecutive cases.*
Patient Safety in Surgery 2014, 8:24.
- II Caesar U, Hansson-Olofsson E, Olsson L-E, Karlsson J, Lidén E. *A sense of being rejected: patients' lived experiences of cancelled knee or hip replacement surgery*
Submitted
- III Caesar U, Karlsson J, Hansson E. *Incidence and root causes of delays in emergency orthopaedic procedures: a single-centre experience of 36,017 consecutive cases over seven years.*
Patient Safety in Surgery 2018, 12: 2.
- IV Caesar U, Karlsson L, Senorski Hamrin Karlsson J, Hansson-Olofsson E. *Delayed and cancelled orthopaedic surgery; are there solutions to decrease the complex set of problems? A systematic literature review*
Manuscript

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Abbreviations

ER	Emergency room
GRADE	The Grading of Recommendations Assessment, Development and Evaluation, a tool used to grade quality of evidence
h	Hours
LOS	Length of stay in hospital
NHS	The National Health Service in England
NRC	Non-randomised controlled trial
NVivo	Is a qualitative data analysis software package. Designed for qualitative researchers working with rich text-based and/or multimedia information, where deep levels of analysis of data are required
OR	Operating room
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses, a checklist used to report systematic reviews
RTC	Randomised controlled trial
SBU	Statens beredning för medicinsk och social utvärdering (Swedish Agency for Health Technology Assessment and Assessment of Social Services)
SPSS	Is a Statistical Package for the Social Sciences (SPSS) and is a software package used in the statistical analysis of data.
SR	Systematic review
THR	Total hip replacement
TKR	Total knee replacement
TTS	Time to surgery

Brief definitions

Definitely cancelled	The patient does not undergo surgery.
Delayed surgery	Surgery scheduled on the waiting list and then re-scheduled
Home pathway	Patients who required unplanned surgery but could not be scheduled within 24 hours after presentation were placed in plaster of Paris, a bandage or a sling before being discharged to their homes to wait for surgery.
Inflow of patients	Every new patient is entered into the electronic operation planning system as a file with a unique patient ID (waiting list). The patient remains in the planning system until the operation is completed, transferred to another care-giver or definitely cancelled.
Operätt	A data system for planning and scheduling surgical procedures
Produced surgery	All the patients who underwent surgery at the current clinic
Qlik View	Qlik View is a data analysis tool that enables access to information in order to analyse it.
Transferred	All planned procedures that the clinic was unable to perform within the three months' treatment guarantee and were cancelled at the current clinic and the patients were transferred to other care-givers.
Waiting list	Every new patient is entered into an electronic operation planning system as a file with a unique patient ID. The patient remains in the planning system until the surgery is performed, transferred to another caregiver or definitely cancelled.

Introduction

Introduction

The Swedish healthcare organisation system

By law, the Swedish healthcare system is a solidarity- and society-funded system ^[1] and approximately 80% of the costs are funded publicly by income tax and approved and managed by the county councils in order to approve and administer health care for all citizens on equal terms. Three basic ethical principles are intended to apply to health care; the perspective of human dignity, need or solidarity and cost-effectiveness. The Swedish government controls all general health policies, while the delivery and funding of the entire service sector largely rest with county councils and regions. The local municipalities are responsible for the care of elderly and disabled people. Most of the primary care centres and almost all hospitals are owned and run by the county councils ^[1-3].

In agreement with the Swedish Health and Medical Services Act (SFS 2017:30) ^[1], the county councils are expected to plan and organise all health care according to needs of the residents, based on political decisions and administrative priorities. Providing equal care means that each county council must prioritise depending on the needs of its citizens. The increasingly high demand for surgical procedures, a demand that is usually

higher than the supply, may result in waiting lists. The prioritisation of waiting lists takes place at clinical level and is performed by the healthcare professions. The waiting lists are often overloaded and the waiting time may therefore be unacceptably long ^[2]. Orthopaedics is one of the specialities for which the waiting lists for many procedures are extremely long ^[4]. Many of the involved individuals are elderly; over 65 years of age. Almost half of all chronic conditions are related to bones, joints and muscles and affect individuals over the age of 65 ^[5].

In this context, it is important to bear in mind that Sweden has one of the world's oldest populations, with almost 20% of its citizens aged 65 years or more ^[6]. This will probably lead to even greater demand from patients in need of orthopaedic surgery procedures over time.

Prioritising

There are two different levels of priorities in Swedish healthcare; first the political/administrative priorities; which concerns the needs of the entire population. The resource allocation is based on needs, for example epidemiological data and may need to be partially prioritised due to resource shortage. Second, at the clinical level, the healthcare profession is

requested to prioritise, the best possible care for each patient at every occasion, based on the given financial frameworks at any time [1, 2, 7].

Prioritisation is primarily based on the three above-mentioned principles, but there are limited analytical tools regulating the decisions that should be made at different levels of the healthcare system, or the allocation of limited resources. There are mainly recommendations rather than clear-cut rules. Swedish health care follows the above-mentioned principles placing the human dignity principle higher than the needs. Moreover, the solidarity principle occupies a higher position than the cost-effectiveness principle [1, 2].

The cost-effectiveness principle should be employed when choosing between two equivalent treatments. If two treatment alternatives are equal in terms of outcome and risks, the most inexpensive should be chosen [1, 2]. Consideration should also be given to whether many patients are able to receive the treatment. For example, if there is a good treatment that is so expensive that only a few patients are considered or a slightly inferior but less expensive treatment which significantly improves the outcomes, the latter should be chosen [1, 2]. The problem is that the cost-effectiveness of different treatment options is not always known.

The healthcare guarantee

In 2005, a healthcare guarantee was introduced in Sweden. This system was

introduced in order to empower the patients' position, increase accessibility to robust health care and guarantee equal admission to all elective care in all parts of the country. The guarantee promises an appointment with a general practitioner within seven days; consultation by a specialist within 90 days; and a wait of no more than 90 days from being diagnosed to treatment being accomplished. From July 2010, the guarantee is regulated by law and includes all elective care in the county councils [8, 9].

If the patient does not have an appointment with a doctor or does not start treatment within the stated time of the guarantee, he/she is given the opportunity of a referral to another healthcare provider. Moreover, the Swedish state reimburses the county councils by the so-called *Kömiljarden* (the waiting-list billion), which was regulated through annual agreements between the government and Swedish Association of Local Authorities and Regions (SKL). The latest agreement was reached in 2014 [9]. The agreements set out certain basic requirements for which no compensation will be paid, if the county councils do not report to the national waiting time database [10-13]. The compensation was distributed to the county councils based on their goal fulfilment, in relation to the country's population [13].

In other words, prioritisation not only occurs at national level, it also affects the clinic and the healthcare professions in

terms of adaptable decisions. Taken together, the law ^[1] is the starting point when it comes to planning and prioritising both emergency (unplanned) and elective (planned) orthopaedic surgical procedures at all levels. It should be borne in mind that elective (planned) surgery is regulated by the healthcare guarantee.

Scheduling surgery

The difficulty when it comes to operating room (OR) scheduling is partially related to the large amount of information that needs to be considered in relation to a surgical procedure. Moreover, this large inflow of information often changes and can change rapidly. Accordingly, the scheduling of surgery means organising and maintaining an active surgical schedule ^[14-18]. The final schedule is a process that can be performed on two paths; an administrative path, with the emphasis on all ancillary processes that support the surgical procedure itself, and the preoperative assessment path, which involves planning and finally scheduling the surgical procedure in order to support and optimise the patients' health prior to the procedure.

Administrative scheduling

The combined information included in the scheduling is interdependent on all collected information. In addition, the information frequently changes during the process (Fig 1). The repeated information

changes make the schedule difficult to oversee, from one day to another. The shortage of hospital beds and the after-care beds are two factors that are well described in the literature ^[19-21]. Several cancellations are due to a shortage of hospital beds, especially when it comes to emergency patients, where a crowded intensive care unit (ICU) is often a reality ^[22]. The lack of healthcare personnel (especially nurses) is a growing problem in Sweden and is one important reason for closed ORs, which may in turn contribute to even longer waiting lists.

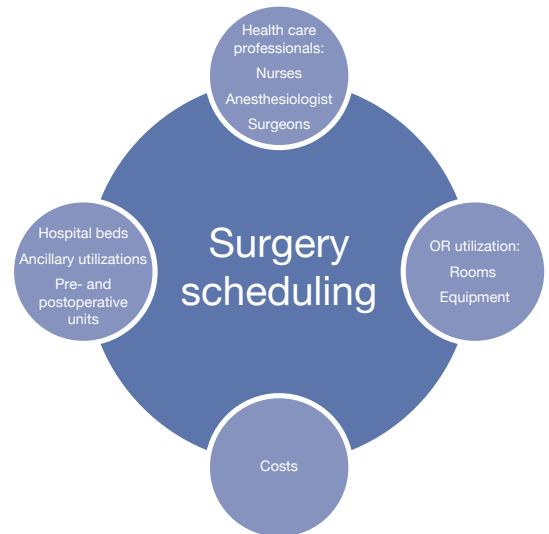


Figure 1 Administrative scheduling of the surgical procedure.

In previous years, scheduling was done by hand on a sheet of paper. Nowadays, surgical scheduling software programs are being used increasingly. These programs enable administrators to collect data on

both planned and unplanned procedures. The program has information about the estimated time of a procedure and individual time for each surgeon. Another active part of the scheduling program is that the process can be communicated between the hospital's management staff related to the ORs, the pre- and post-operative units, consulting office and the surgical co-ordinator. Having all this information collected in one unit simplifies the scheduling [23].

Planning and scheduling a patient

Prior to scheduling the procedure, it is necessary to complete the patients' medical history. In terms of pre-operative assessment, it is possible to evaluate co-morbidities, to limit the risks of complications during the surgical, anaesthetic or post-operative periods. Patients scheduled for elective procedures generally attend a pre-operative assessment meeting one to two weeks before the date of surgery. Hospitals in Sweden usually provide local guidelines, while national recommendations are usually lacking. If the information relating to the patient's co-morbidities and instructions about pre-operative showers or fasting routines are missed before surgery, this might lead to a cancellation [24-27].

Pre-operative assessments are performed in different ways. In the past, patients were usually admitted to the hospital ward only one day prior to surgery, but this resulted in several cancellations, due

to unprepared patients not suitable for surgery [28]. The pre-operative assessment, under the supervision of a nurse, is regarded as having a positive effect on reducing same-day cancellations [29, 30].

Orthopaedic surgery

Orthopaedic ailments do not usually belong to those needing "care for life-threatening diseases which, without treatment, lead to premature death". On the other hand, orthopaedic procedures usually improve quality of life at a reasonable cost [31-33].

The range of orthopaedic surgical procedures covers all the diseases of the musculoskeletal system from minor injuries to major fractures, severe ligament injuries and joint replacements, for example. Diseases of the musculoskeletal system account for almost 50% of the chronic diseases in Sweden. In 2017, orthopaedic surgical procedures accounted for 145,110 (17%) of all 795,086 surgeries performed in Sweden [34].

Musculoskeletal diseases and injuries affect individuals of all ages, from hip dysplasia in newborns to osteoporotic fractures in the elderly, for example.

Planned orthopaedic procedures

Generally, all procedures in which surgery can wait without any risk of increased morbidity or mortality can be called elective. Two good examples are total hip and knee replacements. The level of urgency

of the musculoskeletal injuries is prioritised and, if the surgery can wait, the patient is placed on a waiting list; each surgical procedure often has a dedicated list. Orthopaedic departments therefore often keep several different waiting lists. The waiting time on each of the lists is dependent on the county council's prioritisation and utilisation and the way different diagnoses are prioritised. Consequently, the waiting time varies between different diagnoses and, at least to some extent, also between different parts of Sweden, in spite of the law demanding equal care in the entire country [12].

Unplanned (emergency) orthopaedic surgical procedures

The musculoskeletal diseases or injuries that cannot wait for a surgical procedure include open fractures, neurovascular injuries, joint dislocations, joint infections, unstable pelvic fractures and compartment syndromes. These injuries are transferred to the OR as quickly as possible. If the condition is not immediately life threatening, the orthopaedic procedures may compete, where "the most ill person comes first". Consequently, many of the orthopaedic cases are categorised as a condition that is not life threatening but which, in the worst case scenario, might lead to permanent disability [2].

Sometimes, the operating rooms (ORs) are overcrowded with emergency cases, which may lead to less urgent cases being moved to a waiting list.

It should be borne in mind that there is a wide range of urgency states, related to the patient's medical status, the diagnosis and – not least – the age. For example, a large body of research has focused on patients with hip fractures. Early surgery, within 24 hours, is recommended in order to reduce the number of complications and avoid mortality [35-38]. In terms of ankle fractures, the question of whether they should be operated on within six to eight hours after injury or wait until the swelling has subsided is the subject of discussion [39, 40].

Recently, alternative methods, such as a home pathway for orthopaedic surgical procedures, have been discussed [41, 42]. A patient with an ankle fracture may be sent home to wait for the possible scheduling of his/her surgery. Studies have shown that safe care is possible, provided the prioritisation is made in relation to a well-defined, safe setting [43, 44].

Unplanned surgery is generally not cancelled, but it may be delayed with additional waiting. The additional waiting time may contribute to an increased risk of complications, mortality and the limited well-being of the patients [45, 46] [45-48].

Cancelled surgery

The crowded waiting lists, the high demand from incoming emergencies in need of orthopaedic procedures and the limited resources may lead to congestion among cases and cancellations. All these items might and will negatively affect the

opportunity to perform all the surgical procedures that are planned and will, in the end, result in cancellations. This process often continues with the re-scheduling of cancellations in the best possible manner, in order to disrupt the planned schedule as little as possible. Another important issue is to avoid causing increased and prolonged waiting times. This can often be regarded as a never-ending process. Cancellations usually occur when planned procedures collide with unplanned emergency procedures.

Many studies have described long waiting lists and the need to reduce waiting times for the patients [49-61]. Almost all these studies relate to planned surgery and same-day cancellations. Most of these studies are related to the planning of elective surgery, although an incoming unplanned emergency surgery is often one of the main causes leading to cancellations of planned procedures [23].

In studies reporting on cancelled surgery, unclear terms and definitions are often used. This usually results in difficulty comparing studies [62]. Nonetheless, the reasons for cancellations have been described as either preventable or non-preventable [63]. Moreover, several studies have categorised the reasons as hospital related, patient related and surgeon or anaesthesia related [64].

Patient-related reasons are non-attendance at the appointed time of surgery [65] and cancelling a surgical procedure due to the patient's own needs or requests,

such as work or family reasons. These are reported as frequent reasons for cancelling planned surgery [66, 67]. On the other hand, delayed unplanned surgery is often cancelled because of limited utilisation and organisational reasons. On the other hand, delayed unplanned cancellations are usually due to medical or organisational reasons [68, 69].

Delays and cancellations could have several consequences. First, one serious consequence is that delaying surgery might have a negative impact on the patient's outcome, such as increased morbidity and an increased risk of post-operative infections or other complications. Moreover, the patients' health might deteriorate during the waiting period. On top of this, a study has shown that, in many cases, patients who have their surgery cancelled suffer worse post-operative pain compared with those whose surgery is not cancelled [70]. Several patients who had their procedure cancelled felt that their treatment was incorrect and some experienced fear and uncertainty while waiting for the re-scheduled surgical procedure.

Second, the hospital administration must deal with all the extra administrative paperwork and contact the involved ancillary departments. Further, the revenue from the so-called "Kömiljarden" declines if the healthcare guarantee is not fulfilled. This will lead to further reductions in resources, longer sick listing, as well as lost revenue for the individuals [71].

Suffering

In nursing and caring sciences, suffering is a concept that is mainly related to patients' health and well-being^[72-75]. According to Eriksson^[76], patients' suffering is an important motivation for caring. Eriksson's theory describes three categories of suffering; related to illness, related to care and related to life. The core of the theory is to alleviate the patients' suffering. Consequently, caring for patients who suffer is complicated^[76].

Suffering is difficult to recognise, as the patient is not always able to describe and understand if it really exists. The suffering is the unspeakable; "what the patient does not say". To be more precise, it is what the patient hides, something that is impossible to disclose and express^[77]. In suffering due to illness, the patients often see their ailments as defects or shortcomings and the meeting with the nurse or physician requires both physical and psychological exposure. Patients might then respond differently and in an inconsistent manner to their suffering and shame, by using avoiding behaviours such as withholding information and complaints^[78]. When this occurs, the personal needs of the patient are difficult to meet. This also complicates and opposes the goals of Swedish healthcare policies and laws^[1], which point to the fact that patients are expected to participate in their own care in order to ensure that they are informed of their conditions and that they are involved in the decisions related to their care.

Suffering related to care

Suffering related to care has been described as a consequence of poor communication between healthcare professionals and patients. Because of the poor communication, patients' confidence and trust in health care is lacking^[79]. Moreover, Gustafsson^[80] stated that, when patients felt that healthcare personnel did not understand the whole care situation, they felt that they were not believed and were rejected.

Berglund^[81] described suffering related to care from the patient's viewpoint and revealed four themes: being mistreated; struggling for one's healthcare needs and lack of independence; feeling powerless; and feeling fragmented and objectified^[81, 82]. Suffering from healthcare experiences is also a threat to patients' independence and opportunities to participate in their own health process. Suffering in relation to healthcare needs is regarded as: "unnecessary suffering"^[79].

Adverse events and risks

In a review of 77,000 hospital medical records, almost 8% had sustained injuries related to the healthcare itself. It has recently been reported that approximately 110,000 Swedish patients treated in hospitals each year suffered from healthcare injuries. Of these, 50% were assessed as mild, while 45% led to prolonged hospitalisation^[83].

In Sweden, there is no national estimation of the risks and shortcomings of

information flow in the communication between healthcare professionals and patients. Accordingly, it is difficult to evaluate the number of the healthcare injuries which arise from miscommunication or information shortcomings. Each hospital uses different instruments to evaluate patient satisfaction. In these questionnaires, the question of appropriate treatment is usually included.

Shortcomings in the interaction between a patient and the healthcare professionals are often due to inadequate communication and information. This might in turn lead to safety risks [84]. For example, when healthcare professionals fail to identify the patient's needs and miss approaching risk situations in the appropriate manner, this might lead to inappropriate treatment.

These shortcomings can lead to patients or healthcare professionals not receiving all the necessary information. In a recent study [85] of patients in whom surgical procedures had been cancelled, on most occasions, the patients did not understand why the procedure was cancelled. Taken together, adequate information and meeting the patient's requirements will lead to improved health care.

Reasons for cancellations and delays

Medical reasons

Frequent medical reasons for cancellations or delays include an ongoing

infection, respiratory problems, heart and blood pressure problems and anti-coagulation treatment. In some studies, the patient-reported and medical reasons are merged and reported as patient related [62]. This is one example of the mentioned inadequate terms and definitions that are used.

The orthopaedic surgical procedures that are cancelled for medical reasons or because of inadequate pre-operative preparations could probably be reduced by closer contact with the surgical clinic and admission to a pre-operative clinic [86].

Organisational reasons

It has been shown that organisational reasons lead to a large number of cancellations. These reasons include utilisation shortage, such as a lack of personnel, a lack of hospital beds, a lack of equipment and a lack of OR time, as well as crowded waiting lists, disruptions owing to incoming emergency cases and surgical procedures being prolonged. Several studies have described organisational reasons leading to delays and cancellations [50, 87-91].

Economic view

From a patient perspective, cancelled operations result in changed plans in terms of both social and working life. For patients of working age, it is easy to imagine that changes to an already scheduled surgery might lead to different problems for the individual, the family and in many

cases the employer as well. If a postponed acute condition is causing a work absence, it appears inevitable that the delay will also cause an extension of the inability to work and thereby lead to reduced income for the patient. For many patients, it is very likely that the delay will lead to re-arrangements of practical issues which will also affect family and friends to differing degrees. These re-arrangements might involve a number of daily activities, such as care of children or elderly relatives, pets and so on. They are all situations that might involve the patient's economy [92, 93].

From a healthcare perspective, cancellations for different reasons will disrupt the planning and scheduling in both the short and long run, all adding to less effective production with fewer procedures than planned at the end of the day.

The societal perspective includes all the costs of health care but also all the indirect costs, such as production losses (e.g. sick leave). Indirect costs should also include the cost of patients travelling to and from the hospital, help needed for the patient to reach the hospital and so on [93].

All the delays and cancellations, irrespective of cause and perspective, will negatively affect the cost to society to different degrees.

Aim

Aim

The overall aim of the thesis was to describe the numbers of and reasons for cancellations of orthopaedic surgical procedures at a university hospital department treating both acute and elective patients. Another aim was to determine the waiting times for both elective and unplanned procedures, when cancellations or a delay occurred. A further objective was to elucidate the patients' experiences of being cancelled when waiting for elective surgery. Moreover, a systematic literature review was performed in order to evaluate solutions to the complex problems of cancellations of and delays to orthopaedic surgical procedures.

The questions at issue

- How many surgical procedures were delayed or cancelled?
- What were the reasons for delays to and cancellations of orthopaedic surgery?
- How long was the period from the cancelled scheduled occasion until the procedure was actually performed?
- How did the patients experience the delay to elective orthopaedic surgical procedures?
- Is there any evidence in the literature related to interventions that reduce cancellations of and delays to orthopaedic surgical procedures?

Specific aims

Study I The aim of the study was to describe and analyse the number of and the reasons for cancelling scheduled orthopaedic surgical procedures at a clinic treating both elective and acute patients.

Study II The aim of the study was to elucidate what it means to the patient when planned replacement surgery is cancelled.

Study III The aim of the study was to describe and analyse the number of and the reasons for emergency surgical procedure delays at a clinic treating both elective and acute patients.

Study IV The aim was to systematically search and review the literature for evidence of factors that could reduce cancellations of and delays to orthopaedic procedures.

Patients and Methods

Patients and Methods

In this thesis, three different study designs and methods were used, quantitative and qualitative designs and a systematic review, in order to identify and describe different aspects of delayed and cancelled orthopaedic surgical procedures (Table 1). Studies I and III aimed to observe and describe the numbers and causes

of delayed and cancelled surgery, at a clinic treating both elective and acute orthopaedic patients. Study II was designed to describe patients’ lived experiences of being cancelled from arthroplasty surgery. Study IV aimed to report the presence and quality of evidence in studies aimed at reducing delays and cancellations.

Table 1 Overview of the study designs and samples in each study

	Study I	Study II	Study III	Study IV
Design	Retrospective, observational, descriptive, single-centre study	Qualitative narrative interview study	Retrospective, observational, descriptive, single-centre study	Systematic literature review
Participants	n=17,625 patients scheduled for elective orthopaedic surgery	n=10 patients scheduled and cancelled for knee or hip arthroplasty surgery	n=36,017 patients scheduled for unplanned orthopaedic surgery	n=8 included studies
Method	Descriptive, observational data sampling through hospital records and registers	Strategic sampling Narrative interviews transcribed	Descriptive, observational data sampling through hospital records and registers	Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines Cochrane Handbook
Analysis	Absolute and relative numbers, mean, median and range values, SPSS	Phenomenological hermeneutic NVivo	Absolute and relative numbers, mean, median and range values, SPSS	The Grading of Recommendations Assessment, Development and Evaluation (GRADE)

Ethical considerations

All the studies were approved by the regional ethics committee review in Gothenburg, Protocol Dnr: 531-12.

Studies I and III

To avoid the identification of participants and to ensure anonymity, all personal identifiers were removed and replaced with a sequential number in the dataset.

Study II

All the study participants were given information, both written and oral, that their participation was voluntary and that they could withdraw at any time without providing any reason.

Study IV

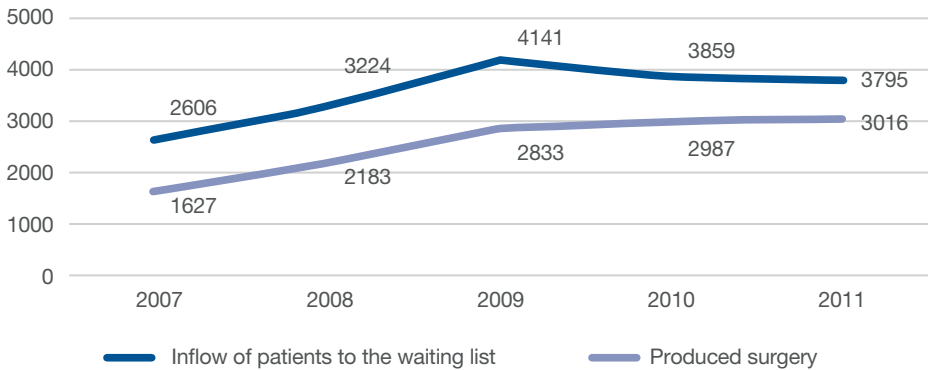
Study IV did not require ethical approval as it was a systematic literature review.

Studies I and III

These studies were descriptive, single-centre studies with retrospective, observational data sampling through the hospital's records and registers. In Study I, the population comprised all the patients scheduled for orthopaedic surgery between 1 January 2007 and 31 December 2011. Study III comprised all the patients scheduled for unplanned orthopaedic procedures, between 1 January 2007 and 31 December 2013. Both studies were conducted at a university hospital

clinic with an annual production of approximately 9,000 planned and acute surgical procedures. The orthopaedic clinic was organised into specialised teams for trauma, joint replacement, arthroscopy, paediatric orthopaedics, foot & ankle, tumour and spinal surgery.

The patients in Study I were only those who were scheduled for joint replacement, arthroscopy, and/or foot & ankle surgery and were then cancelled. In Study III, the included patients were scheduled for unplanned procedures and were then delayed. The collected data included age, gender, diagnosis, reason for cancellation, time of cancellation and length of time until a new scheduled surgery was performed. The age of the patients in Study I ranged between 13 and 99 years and 56% were women. In Study III, the age ranged between three and 107 years and 54% were women. The total inflow of patients to the surgical waiting list of those selected in Study I was 17,625 patients. Of these patients, 12,646 (72%) underwent surgery at the current clinic, while the remainder were either transferred to another clinic or finally cancelled. In all, the difference between the inflow of patients and definite procedures equalled the total number of surgical procedures (Fig. 2).

Figure 2. The Inflow to the waiting list versus the surgery that was actually produced, 2007-2011

During the data sampling period in Study III, 36,017 patients were on the waiting list for unplanned surgical procedures and they all underwent surgery at the current clinic.

Procedure

Study I

The scheduling of surgery in Study I was based on priorities and decisions made by the surgeons in consensus with the patients at the consulting surgery office. A co-ordinator then booked the appointment for the surgical procedure, which means that patient data were entered into the planning system and a file with a patient ID was opened in the electronic planning system (Operätt). The patients were then entered in the system as waiting for elective surgery.

Study III

Three emergency waiting lists ran parallel each weekday with three dedicated trauma ORs on weekdays and two at weekends. One OR was specified for patients with hip fractures and two for general orthopaedic trauma and “home-pathway” patients. We identified patients from all these lists.

The OR scheduling was based on priorities and decisions made by the surgeons while considering the department’s official goal that patients should undergo surgery as follows:

1. All patients with a hip fracture within 24 hours
2. The emergency in-hospital patients waiting on the ward within 24 hours
3. The home-pathway surgery within one to seven days.

To confirm the daily structure and order of priority of the three emergency waiting lists, a regular morning meeting was held at the OR Department. At this time, a senior surgeon prioritised the daily schedule for all the department's surgical procedures, including elective surgery. After the prioritisation was complete, the co-ordinators contacted the wards to confirm the patients waiting for surgery in hospital. Moreover, phone calls were made to those waiting at home, to inform them of either a further delay or a defined and exact time for surgery.

The planning system (Operätt)

In the planning system, data were continuously registered by co-ordinators, surgeons and nurses. A special IT tool, Qlik View (QV), was used as a database and made it possible to identify, calculate and present quality measurements of all activities involving inflowing patients. QV also made it possible to identify all cancellations and delays made in the planning system. The planning system was validated every month.

Statistical analysis

The data in Studies I and III were managed using IBM SPSS Statistics (Version 21). Descriptive data were presented in absolute and relative numbers, mean, median and range values. Graphics were illustrated using Microsoft Excel (Version 2013).

Limitations; Studies I and III

There are several limitations to these two studies. The data are from a single hospital, which makes the results difficult to generalise to other orthopaedic clinics, with different functional characteristics such as size, services provided and case mix. Another limitation could be that different staff categories entered the data into the surgical planning system; Operätt. This could lead to the inconsistent grouping of the reasons for cancellations and poorer reliability of data. As there is both a continuous inflow and outflow from the waiting lists, the given numbers may vary. This also makes it difficult to provide the precise numbers from one time to another.

Study II

The research question in Study II was: "What is the meaning of the patients' experiences when planned replacement surgery is cancelled?". The question focuses on patients' lived experiences and their view of the life world. A phenomenological hermeneutic method was therefore used to investigate the subject.

Lindseth and Norberg^[94] originally developed the method in order to identify healthcare professionals' view of their morals and ethical thinking in complex and challenging care situations.

Phenomenological hermeneutics focuses on interpretations of narratives, which are based on interviews with

persons who have lived experiences of the phenomena of interest. The aim of these interpretations is to find a comprehensive understanding of the participants' experiences. In Lindseth and Norberg's method ^[94], Ricoeur's philosophy of combining phenomenological descriptions with hermeneutic considerations was adopted. From traditions in hermeneutic phenomenology, Ricoeur ^[95, 96] further developed the method in a direction indicating that a pre-understanding is always present in our perceptions ^[97, 98].

According to the method, a pre-understanding is needed and it will largely be seen as being impossible not to interpret one's experiences as a consequence to create meaning in one's lifeworld. It is therefore important to include awareness and openness relating to how part of the researcher's background, beliefs and life experience influences his/her involvement in research ^[97, 98].

Participants

The selection of participants in Study II was strategic and they had all been cancelled from THR or TKR surgery and were in a phase between the cancellation and the new appointment. Ten participants were interviewed from a narrative viewpoint.

Interviews

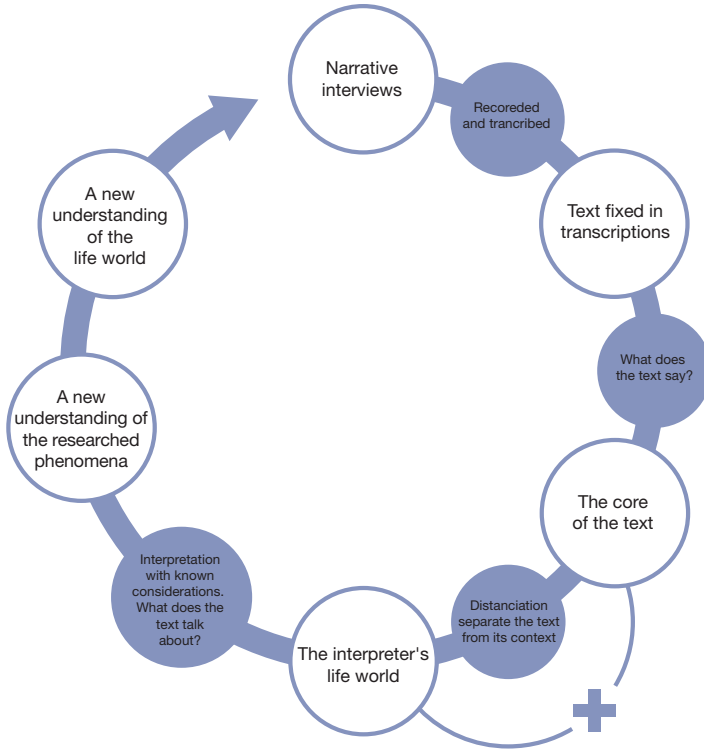
The interviews started with a brief presentation of the participant, the interviewer

and the study. The dialogue then continued with an open-ended question "Can you tell me about the day your surgery was cancelled?". In the interviews, follow-up questions such as "Can you compare your feelings about the cancellation with something else that has happened in your life?" were asked. The interviews ended with a summing up, so that the participant had a chance to explain and add/correct any misunderstandings.

Analysis

In the structural analysis, the text is distanced in the interpretation and the focal point was what the participants said and the analysis. The interviews gave opportunities to acquire new understandings of the effect the cancellations of the planned surgical procedures had from the patient's viewpoint. The transcripts were read several times to create a naïve understanding of what the participant was saying about the studied phenomena (Fig 3).

Figure 3 Ricoeur's theory of interpretation modified from Tan et al. [99]



Ricoeur [100] specified that there are two aspects to viewing texts. The first is defined as a view of only the internal quality of the text. This perspective has no context and has neither an external world nor a viewer. The second aspect is to bring the text back into active communication and combine it with the reader so that new understandings can be reached [99].

The structural analysis generated themes of understandings from the participants' lifeworld. The process of structuring an in-depth understanding involved moving back and forth between explanations and understandings. The analysis went from different parts to the whole picture and backwards and forwards, by comparing the structural findings with the naïve understanding. This process was designed to

validate the trustworthiness of the interpretations. The literature was chosen to explain and deepen the understanding of the phenomena to illuminate the meaning of lived experience and was not supposed to force the interview text or the analysis. Moreover, the findings in the structural analysis were discussed with colleagues to bring new explanations of the participants and understandings of

cancelled procedures.

Limitations

One limitation might be that, in the interviews, the participants were not able to express their thoughts and feelings about the experience of the cancelled procedure. This could, for example, be due to language difficulties, high age or embarrassment about their surgery being cancelled ^[101]. One further limitation was that the researcher was part of the analysis and new interpretations by researchers are therefore limited as the conclusions are associated with the individual researcher ^[102]. Researcher bias is difficult to determine or detect in qualitative research. Another weakness is that the strategic data sampling did not select the “right participants”. Moreover, in the presentation of the vast amount of data, it might be difficult to establish trustworthiness.

Study IV

Systematic literature search

To structure the research question, four items were considered: population, intervention, comparison and outcome (PICO) to guide the search ^[103].

In order to capture as many relevant studies as possible, the search was a mixture of indexing words in blocks combined with OR and finding the relevant literature ^[103].

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)

In Study IV, we used the PRISMA statement ^[104, 105] to help improve the reporting of our systematic review. The PRISMA statement consists of a 27-item checklist and a four-stage flow diagram. PRISMA focuses on randomised trials (RTC), but it can nonetheless be used to report other kinds of studies, such as Study IV; with assessments of interventions in observational studies.

Handbooks for systematic reviews

Cochrane is a healthcare association, collecting and analysing the best accessible evidence to help create well-informed decisions about health. The Cochrane handbook is the official document, which explains the process of producing and it supports Cochrane systematic reviews on the outcomes of healthcare interventions ^[106].

The Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU) handbook is an official document and follows the same steps as in the Cochrane handbook. The SBU evaluates health care and social services in Sweden related to interventions on medical, economic, ethical and social matters ^[103].

The SBU handbook and its checklist for observational study design was used to assess the quality of each study. The checklist measures bias, heterogeneity,

transferability, precision, effect and confounders.

The Grading of Recommendations Assessment, Development and Evaluation (GRADE)

The SBU checklist for observational studies was the first step in the grading, while the second used a classification called GRADE. We identified the bias, heterogeneity, transferability, precision, effect and confounders in each study. This was

then followed by using the SBU’s work sheet on GRADE in each of the studies [103, 107, 108].

The quality of scientific evidence was then evaluated using GRADE on a four-point scale; high, moderate, low and very low quality. The grading of evidence quality started with the design of each study (Fig. 4), before assessing the five reasons for possibly downgrading (Table 2) or upgrading the evidence quality (Table 3) [109].

Table 2 Aspects that might downgrade evidence quality [109]

Factor	Consequence
Limitations in study design or execution (risk of bias)	↓ 1 or 2 levels
Inconsistency of results	↓ 1 or 2 levels
Indirectness of evidence	↓ 1 or 2 levels
Imprecision	↓ 1 or 2 levels
Publication bias	↓ 1 or 2 levels

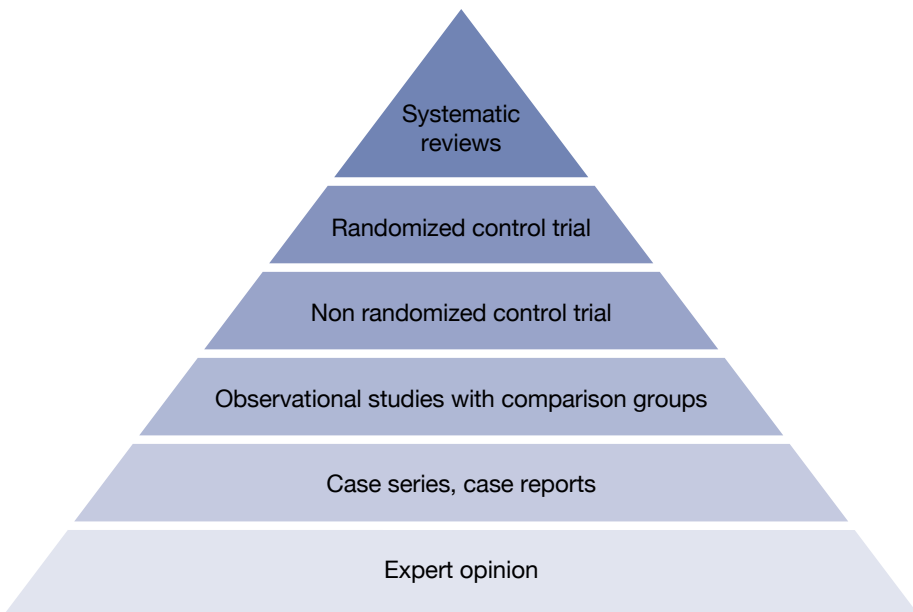
Table 3 Aspects that might upgrade evidence quality [109]

Factor	Consequence
Large magnitude of effect	↑ 1 or 2 levels
All plausible confounding would reduce the demonstrated effect or increase the effect if no effect was observed	↑ 1 level
Dose-response gradient	↑ 1 level

The study design is the most important contribution to the decisions on evidence quality. These assertions are based on the completeness of the effect of the study design on the scientific evidence.

RCT studies begin with (⊕⊕⊕⊕) and can then possibly be downgraded. Observational studies can achieve (⊕⊕⊕○), never higher, and can then possibly be downgraded^[109].

Figure 4 Level of evidence by study design



Systematic literature review and RCT starts on a high level, NRC on a moderate level and observational studies from a low level. Case studies and expert opinion start on a very low level. The pyramid illustrates the hierarchy of evidence which is based on the study method and its rigour and precision. Systematic literature reviews at the top level have the smallest rate of studies, whereas expert opinion on the lowest level have the most^[109].

Limitations

There are several limitations to the study. First, the lack of heterogeneity in the included study interventions, in combination with a lack of calculations, which

made it impossible to perform a meta-analysis. Further limitations are that the grading of GRADE is largely based on the researchers' view of the subject and this might therefore influence the result.

Results

Results

Studies I and III

Purpose

These studies aimed to describe the numbers of and reasons for cancelled and delayed surgical orthopaedic procedures at a clinic performing both unplanned and planned surgical interventions. Moreover, the aim was to calculate the additional waiting time.

Methods

A retrospective, observational, descriptive, single-centre design was used in both studies and data were sampled from

the present clinic's registers. Data were sampled from five years in Study I and seven years in Study III.

Results

In Study I, 17,625 patients were scheduled for elective surgery and, of these, 6,911 (39%) had at least one and some several cancellations.

In Study III, 24% (8,474/36,017) of the patients scheduled for emergency procedures were delayed and re-scheduled at least once, some several times.

Figure 5 Reasons for cancellations of planned surgery

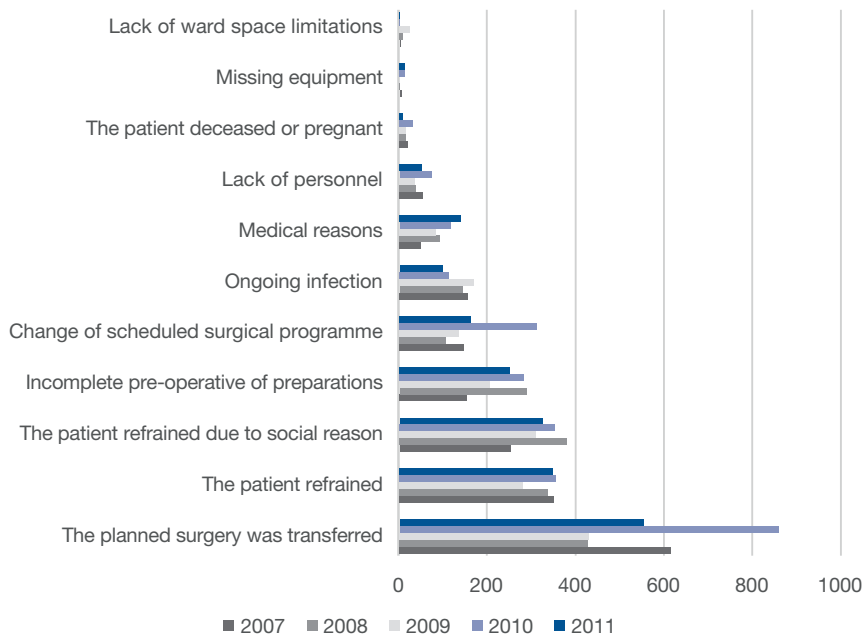
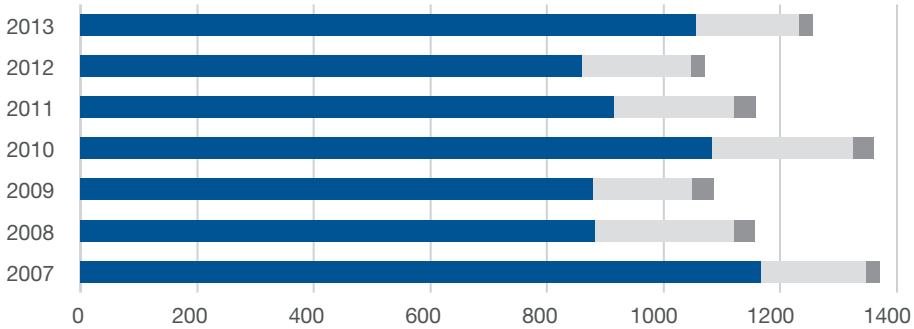


Figure 6 Reasons for delays regarding unplanned surgical orthopaedic procedures



	2007	2008	2009	2010	2011	2012	2013
■ Organisational	1167	885	878	1082	918	863	1057
■ Medical	179	237	170	243	205	183	176
■ Patient related	25	34	38	35	35	25	23

The reasons for the cancellations and delays differed between the two studies. In Study I (Figure 5), the most common reason for cancelling was several patient-related factors; 3,293 (33%). Cancellations due to the treatment guarantee totaled 2,885 (29%) and 1,181 (12%) of the cancellations were related to the incomplete pre-operative preparation of the patients. Organisational reasons accounted for approximately 869 (9%) of the cancellations. In contrast, Study III (Figure 6) revealed that 81% of the delays were due to organisational reasons. Seventeen per cent were due to medical reasons and 3% were patient related.

In 671 (10%) of the 6,911 patients, the cancellation was decided on less

than 24 hours prior to the scheduled surgery. Of the same-day cancellations, 3% (195/6,911) of the patients were scheduled for a joint replacement, 6% (417/6,911) for arthroscopy of the knee and 2% (148/6,911) were scheduled for foot & ankle surgery. The time between cancellation and performed surgery for those 2,639 (38%) patients who had their surgery performed at the current hospital after one or more cancellations varied widely. The median waiting time for the re-scheduled procedures was 54 days for those who had been cancelled once.

In Study III, 21% of all the delayed emergency patients underwent surgery within 24 h and 41%, waited for more than 24 h and up to 3 days, while 17%

waited from 3 days to 1 week or even more than 1 week.

Conclusion

Hospitals and clinics need to deal with the root causes of inefficiency and shortages in many ways. Clarifying the reasons for the cancellations of and delays to orthopaedic procedures is the first and probably the most important step when it comes to dealing with the root causes and shortages at the present hospital, in order to reduce both elective and acute surgery delays and avoid cancellations.

The large number of cancellations in Studies I and III is a major quality problem affecting the individual patient and the actual health care organisation. It is likely that cancellations are also frequent in other specialties. While many of the organisational reasons are avoidable, some of them are still caused by factors that are outside the responsibility of the individual clinic or even the hospital. Many of the delays, such as the medical reasons, appear to be difficult to reduce or eliminate, but some might nonetheless be helped by improving the organisation of pre-operative assessments.

Study II

Purpose and Methods

The aim was to elucidate the meaning of the lived experiences of 10 patients, who had their elective surgery cancelled. The transcribed interviews were interpreted using phenomenological hermeneutic analysis, consisting of a lifeworld perspective.

Results

The ten included participants' characteristics are shown in Table 4. Sixty per cent were women, 60% were undergoing TKR surgery and 50% were employed.

Table 4 Characteristics of participants included in the study

	Age	Type of surgery	Work	Gender	Setting
P 1	62	THR	E	F	Hospital
P 2	55	TKR	E	F	Home
P 3	76	THR	R	F	Hospital
P 4	52	THR	E	M	Home
P 5	56	THR	E	F	Home
P 6	48	TKR	R	M	Home
P 7	47	TKR	E	M	Hospital
P 8	71	TKR	R	F	Hospital
P 9	69	TKR	R	F	Hospital
P 10	74	TKR	R	M	Hospital

E employed, R retired, F female, M male, THR total hip replacement surgery, TKR total knee replacement surgery

The structural analysis revealed four themes from the narratives and transcriptions concerning the participants' thoughts on having hip or knee replacement surgery cancelled (Figure 7).

Naïve understanding

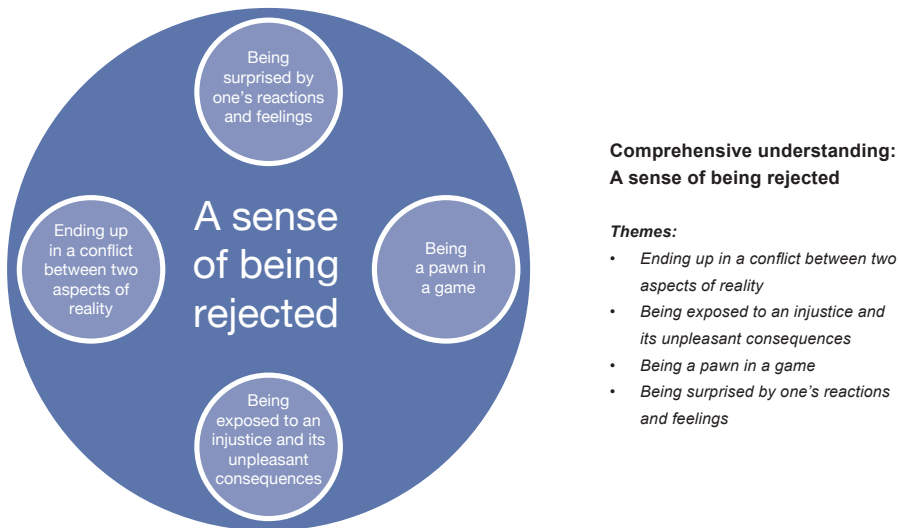
The meaning of having knee or hip replacement surgery cancelled appeared to be

a question of falling into a state of strong feelings and ending up in an awkward and unreal situation. It appeared that the participants' view of becoming well and reclaiming an ordinary life disappeared. Instead of a much-wished-for recovery to which the operation would lead, feelings of hopelessness and abandonment appeared. This also gives the impression

that the participants felt deserted and lonely. The waiting time before the new appointment was both long and heavy and appeared to offer no opportunities

to influence the situation. The lack of information made the participants question whether the hospital's prioritisation was performed correctly.

Figure 7 Themes and comprehensive understanding



Themes

Ending up in a conflict between two aspects of reality

The participants stated that the cancellation was unexpected and very stressful. In the participants' inner reality, no alternative other than their surgery being performed at the scheduled time was in their minds. Their inner (memory-based) reality and the actual external reality did not come together and these two different aspects of reality appeared to come into conflict with

one another. In addition, the narratives gave the impression that the participants were shocked and they said they were unable to take in what was going on when they were given the information about the cancelled procedure. They mentioned that the entire situation felt unreal – like “this cannot happen right now”. One participant described her experience like this ...

(Silence) Hmmm, I was completely blank, it was so unreal. It was so unreal, because I had been nervous about

the operation and... and longed for it as well, so I could be well and be outdoors walking like normal people and start working again and so on... Yes and that was that (the person begins to cry...)

Being exposed to an injustice and its unpleasant consequences

The participants appeared to place great confidence in the surgery and its outcome and mentioned feelings of unfairness relating to the cancellation. Everything had been focused on waiting and planning for the surgical procedure and the aftercare and they said that they had done everything they could to prepare themselves. When the cancellation occurred, they felt ignored and the whole situation was experienced as an injustice and harmed them. It took a great deal of strength to adapt to the new situation. In spite of this, they were the ones who had to deal with the consequences. A man described and presented his feelings in the following manner...

On my way home, I was assaulted by two guys. I took a heavy beating to my neck and back. Then I was taken to the ER at the hospital. It was the same feeling. I was cursed and had done nothing, they were drunk and, yes, ... just messed up ... so they assaulted me and it resulted in my lying there with the after-effects in a hospital bed and I couldn't move ... They hurt me and I was angry. I was just lying there

because of them, just because they were drunk, and it is the same feeling.

Being a pawn in a game

There were narratives about a sense of being treated routinely with a lack of dignity, as though the hospital staff did not pay enough attention. One participant described the experience as being 'a pawn in a game' that the hospital could move around as it pleased. She expected to be treated as more than just a 'number on a list'.

Sometimes I wonder if they know what they are doing with people. It's probably not easy being them, but that isn't what I mean, but (silence) I'm a human not just a number. I am a human being.

Being surprised by one's reactions and feelings

The participants said that it was difficult to meet people and friends who constantly asked how it went, 'Oh... there was no surgery... Oh, when will it be?'. This was experienced as an awkward situation because there was no answer and this reminded them about not being operated on and not being worthy of an operation, like a sense of shame. One participant said that it made him feel embarrassed over the situation and his emotions.

You are reminded all the time. You are reminded when people ask you: 'Oh, you weren't operated on, why?' You have to answer...

The comprehensive understanding

When taking all the findings into account, based on the naïve understanding and themes formulated as a result of the structural analysis, the interpretations of the whole indicate that the meaning of the lived experience of having surgery cancelled appeared to relate to a feeling of being refused, rejected and turned away. Facing the cancellation leaves the impression of being rejected, betrayed and not taken care of. Not belonging and being rejected can in fact be one of the deepest and most painful emotions for humans ^[110, 111]. Social rejection occurs when people are excluded from a social relationship or social interaction ^[112-114]. Moreover, experiences of social exclusion and rejection can last anywhere from a few seconds to many years and people can be rejected by individuals or an entire group of people. Williams and Nida ^[114] explained that a single episode of exclusion immediately threatens four fundamental psychological needs: control, self-esteem, belonging and a meaningful existence. All four of these needs appear to be threatened in the current study's participants. Linked to this, the participants in Study II talked about the cancellations as not being able to make decisions in terms of their own treatment and that they therefore lost control. In addition, they felt worthless, since the hospital did not choose them and this might indicate that their self-esteem was failing. The participants said that they felt excluded and their hope of becoming well

after surgery was temporarily lost.

When the participants in the present study described feelings of being rejected and left out, they used words and metaphors with connotations to physical pain: 'getting hit on the head by a coconut', 'being punched in the face' and 'having the same feelings as being beaten', approaching being really hurt and crushed. Eisenberger's research ^[115, 116] has shown that the feeling of being socially excluded activates some of the same neural regions that are activated in response to physical pain, signifying that social rejection can in fact be painful and this might explain the participants' descriptions.

Conclusion

Study II is the first step towards building a better understanding of patients' lived experiences after having replacement surgery of the hip or knee cancelled and this should be considered as seriously affecting their view of the future and a growing sense of shame. Moreover, it creates a feeling of not being chosen and thereby feeling rejected. The findings highlight the importance of the need for all healthcare professionals to provide patients with empathetic treatment, with appropriate communication in connection with the cancellation. It is to be hoped that the results will produce an opportunity for healthcare professionals to reflect on ways of improving surgical scheduling and better care in cases when a cancellation is necessary.

Study IV

Purpose

The objective of Study IV was to systematically search and review the literature for qualitative evidence of factors that may be useful in order to reduce the number of cancellations of and delays to orthopaedic procedures.

Methods

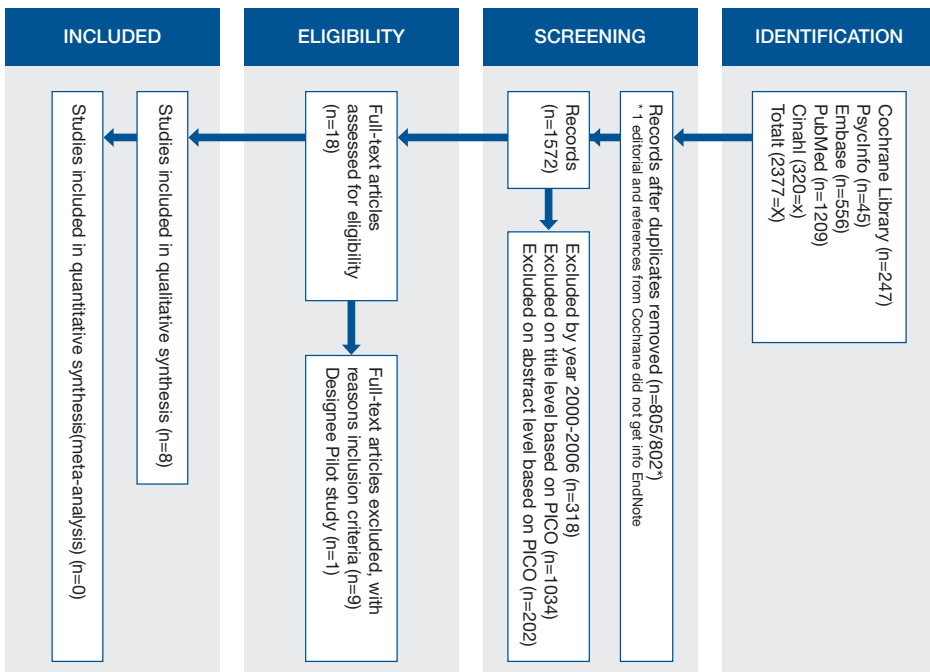
The present systematic review (SR) was conducted following the PRISMA guidelines and the Cochrane handbook. All

peer-reviewed studies reporting on cancellations or delays in patients requiring emergency orthopaedic and/or planned orthopaedic surgery that compared care action/intervention with no action or traditional care were included. In the grading of evidence quality, the GRADE system was used within the included studies.

Results

The electronic search yielded 1,209 studies and eight articles were included in the qualitative syntheses (Figure 8).

Figure 8 Prisma Flow Chart



The characteristics of the included studies are shown in Table 5. The studies originated from the following countries; the UK [66, 86, 117], USA [118], Canada [35, 119], Turkey [120] and Denmark [121]. The study design comprised observational studies with an intervention and control group, six studies were retrospective [35, 86, 118-121], one both retrospective and prospective [66] and two were prospective [117]. The population

sizes ranged from N=44 [86] to N=1,191 [35]. Seven studies comprised patients requiring emergency surgery, six studies were about hip fractures [35, 117-120] and one was on dislocated hip arthroplasty [121]. Two studies included investigations of patients undergoing elective orthopaedic surgery [66, 86]. The intervention periods ranged from nine months [66] to seven years.

Table 5 Characteristics of included studies

Author, year, country	Study design	Study duration (years)	Study groups; intervention 1 vs control 2	Patients (n)	Outcome variables
Bernstein, 2016 USA	Retrospective, observational	4 years	1=183 2= 67	N=389	Time to surgery. TTS Length of stay. LOS
Desai, 2014 Canada	Retrospective, observational	7 years	1=715 2= 175	N=1191	TTS, LOS
Dussa, 2007 UK	Retrospective, observational	2 years	1=16 2=18	N=44	Medically- related cancellations
Gromov, 2015 Denmark	Retrospective, observational	3 years, 4 months	1= 188 2= 214	N=479	TTS, LOS, complications
Marsland, 2010 UK	Prospective, observational	11 months	1=105 2=101	N=196	TTS, mortality
Mutlu, 2016 Turkey	Retrospective, observational	3 years	1=20 2=28	N=116	TTS, complications, mortality
Shangai, 2014 UK	Retrospective (phase 1), prospective (phase 2), observational	9 months	1=118 2= 110	N=228	Patient-related cancellations
Taylor, 2016 Canada	Retrospective, observational	2 years, 11 months	1=204 2= 405	N=609	TTS, LOS, mortality

TTS = time to surgery, LOS = length of stay, UK = United Kingdom, 1 = intervention and 2 = control

The interventions

Fast-track pathway ^[121]

Patients with a suspected dislocated hip arthroplasty (no radiographic confirmation) were transferred directly to the anaesthesia care unit and then directly to the OR. In the usual pathway, the patient was examined by a doctor in the emergency room (ER) and then transported to the radiology department for examination.

Dedicated orthopaedic weekend trauma room ^[119]

A dedicated orthopaedic surgical trauma room on Saturdays and Sundays, designed to increase the volume from five to seven days a week.

Questionnaire the week prior to scheduled time for surgery ^[66]

A five-point questionnaire was designed in phase 1 of the study. This questionnaire was associated with the patient-related cancellations compared in phase 1. The questions included: "Is surgery still required?". In phase 2, the questionnaire was conducted over the phone a week prior to surgery. Phase 1 and phase 2 were compared in terms of patient-related cancellations.

The National Health Service (NHS) guidelines on pre-operative assessment for inpatient surgery ^[86]

The guidelines broadly suggest that an initial assessment of fitness to undergo

surgery should be made directly after the decision to perform surgery is made; the criteria for fitness are agreed in a multi-disciplinary team. The fitness should be established before adding a patient to the waiting list or booking a surgery date. Six and two weeks before surgery, all patients on the waiting list are contacted to confirm that the medical and social circumstances are satisfactory.

An orthogeriatrician was introduced to improve the medical optimisation of the patient prior to surgery ^[117]

The present hospital introduced a care-of-the-elderly physician. In addition, the patients were offered a routine of medical care, as recommended by the Royal College of Physicians and the British Orthopaedic Association. The traditional care was compared with pre-operative examinations by junior orthopaedic physicians.

Additional pre-operative testing ^[118]

Examples included transthoracic echocardiogram; cardiac stress test; carotid ultrasound; rule out myocardial infarction; electroencephalogram; implantable cardioverter-defibrillator interrogation and endoscopy. The usual pre-operative testing compared basic laboratory testing, chest X-ray, ECG and urinalysis.

Additional pre-operative non-invasive cardiac test ^[120]

Examples included a cardiac test:

echocardiography or thallium scintigraphy versus no non-invasive cardiac test.

Not transferred to, instead directly admitted to the trauma surgical clinic ^[35]

A comparison of patients transferred from another hospital and those directly admitted to the trauma centre was made.

The outcomes

Table 6 Outcomes

Outcomes	
The primary outcomes	Time to surgery (TTS) ^[35, 117-121]
	Length of stay (LOS) ^[35, 118, 119, 121]
	Mortality ^[117, 119, 120]
	Complications ^[120, 121]
The secondary outcomes	Medically related cancellations ^[86]
	Patient-related cancellations ^[66]

Risk of bias

Most of the studies had an unclear or low proportion of attrition bias, in contrast to the selection bias, which was generally of a high or unclear degree. Moreover, four of the studies were estimated to GRADE (⊕⊕○○) and four to GRADE (⊕○○○).

Time to surgery, TTS

Five retrospective, observational studies compared the TTS of intervention effect with traditional care. One of these studies explored the effect of additional pre-operative tests versus the usual pre-operative

testing (n=389, p<0.0001) ^[118], while one compared the effect of no additional non-invasive pre-operative cardiac tests with no non-invasive cardiac tests (n=116, p<0.001) ^[120]. Additional pre-operative and cardiac tests had a negative effect on TTS, whereas the management and/or medical therapy after testing was rarely changed. Two of these studies compared the effect of care pathways, one related to hip fractures that were directly admitted to a trauma surgical centre versus those referred from another peripheral hospital (n=1,191, p<0.001) ^[35]. One study of the effects of a fast-track pathway versus

a traditional pathway (n=479) ^[121] reported the differences between the groups (p<0.001). All four of the above studies showed significant improvements. However, in one of these four studies, the effect of an extra trauma room at the weekend versus usual care reported no decrease in the mean time in TTS, from usual care, 31.5 hours, to weekend trauma room, 28.5 hours (n=609, p < 0.16) ^[119]. Moreover, one prospective cohort study (n=196) ^[117] reported the effect of introducing an orthogeriatrician to optimise patients prior to surgery versus traditional optimisation, but it showed no difference between the groups (p<0.71).

The different interventions affecting time to surgery showed both negative and positive results, with a large magnitude effect. The improvement in the effect estimate was limited. The quality of evidence was rated as low, mainly due to retrospective study designs (GRADE ⊕⊕○○).

Length of stay (LOS)

In four retrospective, observational studies, the mean LOS was reduced. In an intervention with an additional pre-operative test versus no additional test (n=389, p< 0.0001), the LOS was reduced by three days ^[118]. The effect of being directly admitted to a trauma-care unit versus being transferred from a pre-hospital was a reduction in the LOS of seven days (n=1,191, p<0.001) ^[35]. The effect of using a weekend trauma room versus usual care reduced the LOS by 2.2

days; this was, however, non-significant (n=609, p <0.16) ^[119]. In a study of the effect of a fast-track pathway versus the usual pathway, the mean LOS was reduced by 4.6 days (n=479, p=0.001) ^[121].

In all, the LOS may be reduced by the above-mentioned interventions compared with usual care. The quality of evidence was rated as low, mainly due to retrospective study designs. Low certainty of evidence (GRADE ⊕⊕○○)

Mortality

Two retrospective, observational studies described the effect of care actions on the risk of mortality ^[119,120]. In one of the studies, no additional pre-operative cardiac tests versus traditional tests were reported in terms of one-year mortality after hip fracture surgery (n=116, p<0.137) ^[120]. The difference between the groups was not significant (n.s.). The other study defined 30-day mortality after the implementation of a weekend trauma room (n=609, p<0.24) ^[119]. Thirty-two patients (5.3%) died within 30 days of their admission. The mortality rate was not affected by introducing a dedicated weekend orthopaedic trauma room. In a prospective cohort study, an orthogeriatrician was introduced to perform assessments on patients with hip fractures prior to surgery (n=196), ^[117]. The study reported that mortality at one month was the same in both the intervention and traditional care groups. Moreover, mortality at three months was 9/107 patients in

the intervention group and 15/101 in the traditional care group ($p < 0.27$).

It is uncertain whether no additional cardiac tests or a weekend trauma room will affect mortality. Moreover, when an orthogeriatrician performed pre-operative assessments on patients with hip fractures instead of the usual care, the mortality risk was not reduced. The weakness of the study was not including more parameters, such as the considerations of orthopaedic ward and necessary multidisciplinary support. Very low certainty of evidence (GRADE $\oplus\text{O}\text{O}\text{O}$).

Complications

One retrospective, comparative cohort study ($n=479$)^[121] reported complications both intra-operatively and post-operatively and the effect of being admitted to a fast-track pathway versus a traditional pathway. The study revealed that the in-hospital complication rate was reduced by 4% and the intra-operative complications by 2.1%, after being admitted to the fast-track pathway, however, there was no significant difference between the groups ($p < 0.2$). One retrospective, observational study compared the effect ($n=116$)^[120] of additional non-invasive pre-operative cardiac tests on post-operative and pre-operative complications, such as pulmonary emboli, wound infections, compression ulcers and urinary tract infection, and reported that there was a significant difference between the two groups ($p < 0.05$). The group that

underwent additional tests had an increased risk of complications.

It is uncertain whether the negative effect of additional pre-operative cardiac tests may reduce complications. However, one of the ways to prevent post-operative complications in the elderly when it comes to hip fracture surgery is cardiac tests. Since the study design was retrospective, the limitation might be that the data on the complications might not have been observed in the patient records and hospital registers.

It is uncertain whether complications will be reduced by introducing a fast-track pathway. It is uncertain whether the negative effect of additional pre-operative cardiac tests will improve complications. The quality of evidence was rated as low, mainly due to the fact that the studies had retrospective designs, with very low certainty of evidence (GRADE $\oplus\text{O}\text{O}\text{O}$).

Medically related cancellations

In a retrospective study^[86], compliance with the NHS National Good Practice Guidance on Preoperative Assessment for Inpatient Surgery was evaluated. Forty-four elective orthopaedic patients of 1,110 (4%), whose operations were cancelled for medical reasons, were studied related to the use of the guidelines; (28/44) 64% did not undergo a pre-operative assessment. Sixteen patients underwent a pre-operative assessment, where three of these 16 were cancelled in spite of the pre-operative assessment.

The study has a serious lack of directness, since the relevance of the comparator to the intervention had no relevant baseline variables. The magnitude of effect was low (0%) and the precision was neither estimated nor reported. It is very uncertain whether the implementation of the guidelines affects the rate of medical cancellations. Very low certainty of evidence (GRADE ⊕○○○)

to reduce delayed and cancelled orthopaedic procedures are on a low level. There is a need for more research with robust study designs that enable more and higher grades of evidence.

Patient-related cancellations

One observational study comprising a retrospective analysis in phase 1, without a questionnaire, and a prospective analysis in phase 2, using a questionnaire (n=228), were conducted [66]. The study included planned surgery and the objective was to reduce same-day patient-related cancellations. These cancellations were reduced by 8.4%, but no significant difference was reported.

The publication bias was high, as the questionnaire was produced from the clinic's best practice and was not validated. Moreover, the completion rate was not reported, even though the study had a prospective design in phase 2. The magnitude of effect was low (0%) and the precision was neither estimated nor reported. It is uncertain whether a questionnaire affects the rate of patient-related cancellations. Very low certainty of evidence (GRADE ⊕○○○)

Conclusion

It is evident that effective interventions

Discussion

Discussion

The Swedish healthcare system

The goal of this thesis was to describe the numbers and reasons for delays to and cancellations of specialised and standard orthopaedic procedures, to determine the waiting times and to describe patients' experiences when their surgery was cancelled. Moreover, the goal was to search for interventions in the literature that can reduce delays and cancellations.

When care is supposed to be equal for all citizens, as it is in the Swedish healthcare system, there is a need for rules and regulations governing how to make priorities and decisions on reasonable, fair grounds. Collecting and applying the best available knowledge in this respect is very important in a system of this kind. Although there are national ethical priority guidelines^[1], there are no national priority orders, only recommendations^[2, 122] on how to tackle these challenges.

The basis for priority is ranked as follows.

In the first part, there is an ethical platform – and a core value with principles that support decisions based on priorities; “the difficult choices of care”.

1. The human dignity principle
2. The need solidarity principle
3. The cost-effectiveness principle

These principles are ranked in the order just shown.

The second part is the basis for priority lists.

1. Care of persons with life-threatening acute diseases, severe chronic diseases, palliative care and reduced autonomy
2. Prevention, habilitation and rehabilitation
3. Care of people with less severe acute or chronic diseases, but where treatment is medically justified
4. Care for reasons other than illness or injury

The present thesis shows that the actual hospital, like most other Swedish public hospitals, has been struggling for many years with an imbalance between demand and supply, i.e. the number of patients who need care and the actual number of patients treated is not equal.

Organisational reasons were responsible for approximately 80% of the delays/cancellations of all emergency patients in Study III. The main reason was that available operating rooms (ORs) were either lacking or occupied, while the absence of staff and/or equipment and too few available hospital beds also contributed. Not performed or missing

necessary preoperative medical and laboratory examinations were also frequent reasons for both delays and cancellations. When the resources are less than the actual demands, illustrated here by the finding that 24% of all patients in need of emergency surgery were delayed, the question of which patients are in greatest need of care is brought to the fore.

One large and probably increasing problem in the Swedish public healthcare system and undoubtedly a major reason for delays and cancellations is the seeming and rapidly increasing number of vacancies or shortage of specialised nurses needed to keep the public hospitals OR and beds open and functioning. Improving the working conditions, including better payment for the highly specialised nurses essential for the treatment and care of orthopaedic patients preoperatively, during surgery and postoperatively, would most probably make this part of public health care more competitive and reduce the number of specialised nurses lost to private enterprises [123]. This might be one, perhaps the most decisive factor in starting to reduce the number of delays and cancellations in orthopaedic surgery.

Long waiting times for health care have been a much debated question over at least the last four decades [124] and they continue to be an important focal point in Swedish welfare politics. Reducing or even eradicating waiting times is a vital issue. At the same time, it is an enormously problematic task for the Swedish

political system [125].

Between 2009 and 2011, the health-care queues for surgery in Sweden decreased. However, between 2013 and 2017, the number of patients waiting more than 90 days for surgery increased from 12% to 26% [12]. Moreover, the National Board of Health and Welfare has stated that improved accessibility to surgery takes place partly at the expense of other patient groups with other care needs [83].

Study I showed that the median waiting time for those cancelled from elective planned surgery once was 54 days and for those cancelled four times 96 days. It must be remembered, however, when, for instance, the waiting time before the cancellation had been 60 days, the waiting time for those cancelled four times was as much as 156 (60+96) days in total. These waiting times fall a long way short of meeting neither the stipulated health guarantee time limits nor the patient's expectations of care and, in addition, they quite probably lead to increasing costs.

One method used to reduce the number of cancellations is continuous and repeated contact with patients on waiting lists in order to update the current information on their health status and the need for care. Recent studies [66] have revealed that these routines can reduce the number of cancellations of planned surgery.

In Study I, the reason for a considerable number of cancellations fell under the heading of "no indication" for the

intended procedure. Many cancellations of this type might be easy to foresee and thereby prevent, provided that the above-mentioned routine of active contact between the patient and the hospital was in place.

Before any definite scheduling for surgery, comorbidities must always be carefully investigated and analysed and should not come as a surprise, when the patient arrives for a scheduled appointment. This can be seen in Study I ^[67], where 12% of the cancellations were due to insufficient medical assessment and/or arrangements related to preoperative fasting or a lack of skin preparation in patients. This seemingly natural step in determining the patients' operability could substantially reduce the number of delays or cancellations.

Waiting list inflow and outflow

Queues and subsequently extended waiting times are growing, when the difference increases between those receiving care and the number of patients in need of care. Information on the inflow and outflow of patients on the waiting list is the basis for measurements of queue balance.

Queue balance is the percentage difference between outflow and inflow and the percentage by which production differs from inflow. A negative queue balance indicates that the number of new appointments or surgical procedures

performed is fewer than the number of added patients ^[13].

For example, the differences in Study I's inflow and outflow in 2011 was (outflow) 3,016 / (inflow) 3,795 = -0.20; in other words, the outflow was negative and 20% less than the inflow of 3,795. Among other things, a negative queue balance generally means that a deterioration in care-guarantee compliance can be expected; the greater the imbalance, the greater the deterioration ^[13]. Study I showed that 29% of the cancellations were made because the patients had waited too long according to the healthcare guarantee and for that reason the patients were referred to other care-givers.

Prioritisation

When prioritising health care, the health services, for instance, hospitals, are expected to follow the government rules and guidelines for healthcare priorities ^[1, 9]. The law, on the other hand, regulated the care guarantee (the time limits for waiting) from 2010. Changes to this law in 2015 added requirements about the care guarantee (SOF 214: 821) and has since protected the patient even more ^[126]. As a result, the county councils are obliged to provide care within the care-guarantee time limits.

According to this law (guarantee), the patients with the greatest needs have the highest priority to receive care. In areas where patients need emergency care, the

healthcare guarantee is of less importance, as the guidelines for priorities within the healthcare service declare that patients with the greatest needs (i.e. emergency) should be given the highest priority. The results in Studies I and III showed that “organisational reasons” for cancellations were much more frequent for emergency procedures than elective ones. The waiting time for “delayed emergencies” was more than one week in 7%, while 17% of the patients waited from three days to one week. In most cases, these patients were waiting for fracture surgery.

Several patients diagnosed with a fracture, for example, returned to their homes after being temporarily treated, e.g. with a brace or cast, to wait for final surgical treatment. Most of these patients had wrist or ankle fractures. Studies have shown ^[43, 127] that this might be a safe pathway if the patients are properly selected and informed.

The care guarantee does not control the quality of the care – either the care processes, or how to reach and contact the healthcare provider for time scheduling, for example. These aspects are central to the patient and might influence the patients’ overall experiences of health care and its availability. From the patients’ perspective, the fact that the care-guarantee limits are kept is not enough when it comes to the patients’ view of healthcare availability, as revealed in Study II ^[128].

The participants in Study II revealed that it was difficult to know who to talk

to, how to reach the clinic and, moreover, after a cancellation, to receive answers to their questions. This study showed that several of the participants had to wait for weeks for a new appointment. This generated a long period of uncertainty and doubt and for some participants the legitimate question: When will I be able to return to work?

Cancelled surgery

The crowded Swedish waiting lists are mainly described in terms of waiting times in days and hours, but poorly with regard to the causes of waiting or the reasons why surgical procedures are delayed, re-scheduled or cancelled ^[13]. Moreover, in the Swedish national statistics on waiting times, the wait for additional medical examinations or investigations, such as control radiographs, and the time to follow-up appointments, for example, are neither added nor included. What is more, the statistics do not say anything about the quality of care in terms of mortality, complications and quality of life ^[13].

The results in Study III showed that the most common reason for a delay was that an emergency patient (reported as an organisational reason) was given higher priority. This is in contrast to Study I, where organisational reasons were less common. It was apparent that emergencies more frequently delayed a subsequent emergency patient rather than an elective/planned patient. The problem

with elective patients whose surgery was cancelled because of incoming emergency patients was smaller than we originally expected. One reason for this could be that the elective patients were prioritised because of the presence of the healthcare guarantee but also as an effect of the so-called “kømiljarden” (the waiting list billion). This was an economic incentive from the government to the counties responsible for health care to reduce the waiting times for treatment. It is not unlikely that these factors improved their eagerness to treat waiting, elective patients, to some extent at the expense of emergencies.

Study III revealed that 21% of all the delayed emergency patients underwent surgery within 24 hours, while 41% waited for more than 24 hours and 17% waited from 3 days to 1 week or even more than 1 week.

It should be borne in mind that the present studies were conducted at a university hospital, with possibly longer waiting lists than other hospitals [12, 129]. The reason for the longer waiting lists at university hospitals might be that they commonly deal with a high volume of complex care patients transferred from surrounding, less specialised local hospitals. Consequently, the number of emergency patients might vary a great deal, making the situation with overbooked ORs even more complex, which is consistent with extended waiting lists and increasing waiting times.

Studies I and III reported high numbers of cancelled elective (39%) and delayed emergency (24%) surgical procedures. The numbers persisted throughout the study period. This leads to the question: “How and why do these limitations continue year after year?”.

One explanation could be that the persistent long waiting lists and the many delays and cancellations finally become a state of “normalisation”, which grows in the organisation, as many healthcare organisations apparently suffer from performance deviation at least to some extent. This will in turn lead to failure to meet expectations from the government and citizens and might influence every aspect of production, efficiency, quality, safety and any other goal against which the hospitals may measure themselves. There is a risk that the “normalisation” of deviance might even damage the safety culture, leading to an increased tolerance of errors and the acceptance of increased risks at all times [130].

The administration of delays and cancellations thereby becomes normalised, in the everyday work of the healthcare professions.

Suffering related to care

The theme “Being a pawn in a game”, in Study II, is understood as being powerless, as if someone else is deciding over your life situation. The participants appeared to wonder whether they were still

being regarded as an individual or just a number on a list. Suffering from care is when the patients' perspective on illness and health is overlooked and they are excluded from taking part in their own care. Berglund ^[81] described being mistreated as errors occurring and patients feeling that no one at the hospital seriously cared or took any responsibility.

“Being exposed to an injustice and its unpleasant consequences”, a theme from Study II, describes the participants felt hurt after the cancellation, described as being knocked or beaten. Disappointments by not undergoing the surgical procedure was reacted by for example by laying down in the bed the whole day,

The participants in Study II said that the message that their surgery had been cancelled was surreal and, in many ways, difficult to understand and accept. The participants described it as being in a bubble and being numb. They needed some time to understand and accept this information. Communication is an important instrument designed to improve the relationship between patients and healthcare personnel. In Study II, the participants claimed that the cancellation was communicated poorly and that they felt that the healthcare professionals did not understand how much the participants were (negatively) affected by the cancellation. Moreover, the information about why the cancellation occurred and what might be expected next was experienced as both limited and incomplete. Most of the participants did not

really understand why the procedure had been cancelled. These factors confirm the results of another recent study ^[85], where patients' experiences after the cancellation of surgery revealed that no formal information of the reason was given in several cases and patients reported dissatisfaction with the explanations that were provided. Consequently, in Study II, the participants felt unfairly treated because they were unaware of why the cancellation had occurred and they therefore wondered if the decision about the cancellation was made fairly. Healthcare professionals and organisations therefore need critically to reflect on their professional role in this context. One of the health profession's obligations is both to make sure that the patients participate in their own care and to adopt a communication style that is appropriate and understandable to each patient. This is clearly described in the Swedish Health Care Act (2017) as: “Care should be designed and delivered as far as possible in consultation with the patient”. The requirement is also to tailor the information so that the patient is in the best position to make his or her own decisions ^[1].

Interventions to prevent delays and cancellations of orthopaedic surgical procedures

The evidence in the systematic review was of low grade. In spite of this, the interventions to reduce cancellations and

delays included several good ideas. Five of the studies involved patients who were delayed while waiting for the treatment of hip fractures. Some of the proposed interventions suggested carefully considering additional tests and cardiac examinations before surgery, while others suggested that different pathways had a significant effect on the “time to surgery” and the “in-hospital stay”. Patient- and medically related cancellations decreased when the patients were contacted by telephone one to two weeks before surgery. These findings might be useful in achieving a better understanding of how to reduce the numbers of delays and cancellations.

Economical aspects

The costs of handling many of the re-bookings are expenses, which should not occur and could be avoided. For example, there are systems where patients themselves choose their time for the surgical procedure and, in these cases, it has been shown that cancellations decline considerably ^[41,131]. Cancelling one’s own surgery should only be allowed within certain limits.

The group of people who need care will most probably continue to increase with the present increase in life expectancy. This means that the costs of health care will rise even more, while tax revenues for running the healthcare system will probably not increase at a similar rate. The

difference between the estimated revenue and the costs in 2030 represents a deficit of approximately 30% of the costs in 2030 ^[132]. The question is how these needs will be financed within the framework of the Swedish healthcare system; care on equal grounds, regardless of income. The care guarantee is largely a political indicator, like a policy document.

What healthcare guarantees, if any, can the Swedish population look forward to in the future? Politicians control care by guaranteeing care and prioritising certain groups, but to implement the changes that guarantee and prioritise politically will be costly and there is a need for a different management in the future.

Methodological considerations

Methodological considerations

One strength of this thesis is the combination of studies with different designs; two register studies, a qualitative study and a systematic literature study, where the different studies work together as a main thread with the aim of highlighting the complex set of problems with delays and cancellations in orthopaedic surgical procedures.

Retrospective register data in Studies I and III

Studies I and III were hypothesis generating. We assumed that cancellations are generally negative, not only for the individual patient's quality of life, for the economy from every perspective and the orthopaedic organisation, but also from a medical perspective.

The register Studies I and III involve a thorough evaluation of the number of cancellations and/or delays and their reasons and the included patients fell into several different categories. All the subjects notified in the registers were included consecutively. First, the data covered all the patients that were registered for orthopaedic surgical procedures, but they were subsequently limited to only those who had been cancelled during a time period of seven years. Different kinds of procedures, as well as different ages and

sexes, were included in Studies I and III.

The data from the hospital registers were used to evaluate the reasons for cancellations and represented an important step in the scientific process. Initially, the reasons for the delays or cancellations varied a great deal. For this reason, a clarification of the causes leading to delays and cancellations was needed. Consequently, we categorised the data on cancellations, using the overall descriptions in the literature, as patient-, organisation- and medically related.

When register data are used, it must be remembered that the validity can never be better than the data on which the register is based. The observational data in Studies I and III were collected from the operating schedule IT-system, Operätt, and patients' medical records. These data were then transferred to QlikView, a quality tool, which can be used to arrange data in different categories. The QlikView data were validated once a month during the study period. In Operätt, several different healthcare professionals record the data and the human factor, such as underreporting or errors in choices of terms, must be taken into consideration. Moreover, the number of the inflow and outflow patients on the waiting lists is continually changing. It is therefore difficult to give an exact number of patients from

one day to another. Taken together, the limitations of register-based cohort studies may include the limited availability of data and underreporting, or data which are not adequately handled.

Observational studies are evaluated in terms of both internal and external validity. Internal validity refers to the strength of a conclusion reached on the basis of evidence and reasoning. Our conclusions relating to the sampled data were therefore drawn unanimously with national and locally established guidelines in order to ensure reliability. The most important issue in the assessment of data is whether the observed changes can be derived from the studied subject and are not related to other possible causes. It is therefore important that observational research considers alternative explanations for study results, so-called confounders. We therefore discussed the variability in results continually during the analysis period. We are aware that the internal validity might be limited by the absence of controls, but our goal was to describe the problem.

External validity is described as the degree to which the conclusions in a study would hold for other subjects in other places and at other times. The context in Studies I and III is based on a healthcare system that is publicly financed. Accordingly, the results in that respect could be applied to similar orthopaedic departments.

The large cohorts in Studies I and III strengthen the results, giving them greater power. Basically, a register study is a prospective or retrospective observational study of an open cohort. We therefore considered the rules of sample size as in observational studies. Since the hospital's register continually included patients on a daily basis, there was no need to calculate sample size. We were interested in the trends over time and expected to find delays and cancellations in every year that was studied.

Trustworthiness and qualitative method in Study II

In contrast to Studies I and III, all the data in Study II were sampled from a small selective group of patients in order to highlight the meaning of being cancelled from a planned surgical procedure. In this study, the sampling was strategic to include only patients cancelled from a knee (TKR) or hip arthroplasty (THR) procedure. All the participants in that study were between the cancellation and an appointment for new surgery, i.e. being rescheduled. These strategic considerations were discussed before the selection and were supposed to cover the specified data in the complete group of patients undergoing TKR or THR. The selection of participants was evaluated after the interviews and the inclusion of data was covered.

According to Lincoln and Guba ^[133],

the credibility, dependability, confirmability and transferability of a qualitative study serves as a guide to its trustworthiness. With reference to the credibility of a study, it is important that the research is carefully disclosed and reflected upon throughout the entire process of its context ^[134]. In Study II, the surgical co-ordinator assisted with the selection of patients after being informed of the study's inclusion and exclusion criteria.

According to Dalberg et al. ^[98], the quality of a narrative rests on the interaction between the interviewer and the interviewee. People do not simply share their narratives of lived experiences just because someone claims to be a researcher. Sharing one's life experience is a matter of trust. After the interviews in Study II, some of the participants expressed relief, as, for some, this was the first time they had shared their stories. This is an indication that the interviewer was able to establish a safe environment for the participants.

Dependability, according to Pollit ^[101], is an evaluation of the quality of the integrated processes of data collection, data analysis and theory generation. One approach to assess the dependability of data is to clarify the research process ^[101]. In Study II, we attempted to give a view of the process by describing the three steps of the analysis, with examples from the structural analysis and by providing rich, detailed descriptions supporting the findings with quotes from the original

transcripts. Taken as a whole, we aimed to give the reader the opportunity to assess the trustworthiness of the research clinic that had been chosen.

In qualitative research, the researcher, who also is a part of the phenomenon that is being studied, is the main instrument ^[102]. According to Pollit ^[134], confirmability is reached by the capacity of the research method to produce data, which are as objective as possible, and the researcher's honesty in terms of clarifications of the data. In Study II, the researchers' pre-understanding was reflected upon, with the aim of avoiding the risk of weighting too much opinion in the interpretation of the narratives.

When it comes to transferability ^[134], it is important to note that Study II's findings cannot be generalised to other circumstances. Before using the findings in another context, a re-contextualisation needs to be undertaken. Study II's findings provide information that can be relevant for future researchers, healthcare professionals and patients.

Searching and grading systematic literature reviews in Study IV

The aim of Study IV was to assess the literature in terms of the effect of interventions that might reduce cancellations and delays. The search was conducted using terms relating to PICO (patient, intervention, comparison, outcome), such as waiting time, waiting list, emergency,

elective, cancelled, delay and so on. This study also included both emergency and elective procedures, as these two different categories need care with different treatment protocols and different time aspects. It might therefore have been more correct to divide the search into two areas, emergency and elective, but we would then have missed the problem of mixed procedures, which has been described as the core of the problems.

Grading evidence is always somewhat subjective, even if there are validated tools that can be used. The screening and grading in the present study were performed by two researchers, with a senior researcher, who controlled all the discrepancies which were discussed during the process. This process strengthens the validity of the grading and screening process.

The external validity of the evidence in the eight reviewed studies suggests interventions which could be generalised to and across other situations where orthopaedic surgical procedures are delayed or cancelled, especially related to patients undergoing hip fracture surgery.

Taken together, the methodological strength of this thesis is to describe the patients' situation in different ways, using both quantitative and qualitative analyses. Moreover, systematic analyses to describe methods to alleviate at least some of the problems reported in Studies I-III, related to patient care and healthcare organisation, are a further strength.

Future research

Future research

This thesis is the first step towards both forming an understanding of the incidence of causes of delayed and cancelled orthopaedic procedures and reflecting on how this affects the healthcare organisation at both national and county council levels.

Most of all, healthcare professionals need to be aware of this problem which affects the patient negatively on many levels; social, work related, mental health and well-being in general. Moreover, the risk of increased pain and limited mobility should be borne in mind. Further, the costs will increase, while the expected result of the planned procedure is not achieved. The risk of medical complications for delayed or emergency orthopaedic procedures increases, along with extended waiting. For some patients, waiting for elective surgery might increase the risk of a deterioration in co-morbidities. There is a major gap in knowledge, when it comes to increased risks of complications such as infections or re-operations related to delayed and cancelled procedures.

Patients need specialised, well-adapted care in the context of being cancelled, an area which is in need of further development. This includes knowledge of how to provide information about a delay or cancellation to a patient, as well as how the information is received and understood by patients.

Study II clearly showed that delivering negative information is challenging. To

improve the situation for both the healthcare professionals and the patients, there should be a clear-cut action plan for the way difficult messages are given. This should be worked out in detail by the hospital's healthcare professions, including where to give the information, to whom the information should be delivered, when to give the information and, finally, the content of the information. Information about the continued care and finally an apology should be included in this plan.

A national healthcare plan for when surgery is cancelled, using step-by-step guidelines on how to perform the most suitable actions and care, is needed. A plan of this kind should be based on further research.

The "home pathway" described in Study III is a fairly new phenomenon in emergency care. The organisational outcomes and waiting times, as well as patients' experiences of waiting at home for emergency orthopaedic procedures, are areas for further research.

Health care is in need of further research in terms of interventions designed to prevent delays and cancellations. Study IV showed that there is a need for more research with robust study designs that enable higher levels of evidence relating to possible actions to avoid cancellations.

A national estimate and reports of cancelled surgery might be a good start to clarify the situation in Sweden.

Conclusions

Conclusions

The number of cancellations of planned orthopaedic procedures in Study I was high; of 17,625 patients scheduled for elective surgery, 6,911 (39%) were cancelled at least once. Many of the cancellations appear to be possible to reduce or eliminate, while others are more or less unavoidable or might be caused by factors that are outside the responsibility of the individual clinic or even hospital. By clarifying the reasons for the cancellations, everyone involved will acquire a better knowledge to improve and develop new routines to reduce the number of cancellations. One way of influencing the high rate of cancellations might be to involve the patients themselves to a greater extent in the overall planning of the care process.

The high number of cancellations shown in this thesis is a major quality problem affecting the individual patient and the actual healthcare organisation. It is likely that cancellations are also frequent in other specialities.

Hospitals and clinics need to deal with the root causes of inefficiency and shortages in many ways. The large number of organisational delays in Study III is a major quality problem affecting the individual patient and the actual healthcare organisation and it very probably leads to increased costs, including prolonged sick leave. Many of the delays, such as several of the medical reasons, appear to be impossible to reduce or eliminate, but some might

nonetheless be helped by improving the organisation of preoperative assessments.

Study II is the first step towards building a better understanding of patients' lived experiences after having replacement surgery of the hip or knee cancelled. This study improved our understanding of the participants' experiences of the cancellations, which should be considered as seriously affecting their view of the future; for instance, a growing sense of shame and a feeling of not being chosen and thereby feeling rejected. The findings also highlight the importance of the need for all healthcare professionals to provide empathetic treatment to patients and the appropriate communication relating to the cancellation of a surgical procedure. The results might therefore provide an opportunity for healthcare professionals to reflect on ways to both improve surgical scheduling and care in cases when a cancellation is necessary and to treat patients on waiting lists more effectively.

Study IV provides an insight into the necessary answers to some solutions to reduce delays and cancellations in orthopaedic surgery. It is, however, evident that evidence relating to the effects of interventions in delayed and cancelled orthopaedic procedures is limited. There is a need for more research with effective, robust study designs that enable higher levels of evidence.

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