

# **Consequences of meticillin-resistant *Staphylococcus aureus* (MRSA) acquisition**

**Patient experiences and interactions in health care and daily life**

Eva Skyman

Department of Infectious Diseases, Institute of Biomedicine,  
Sahlgrenska Academy, University of Gothenburg



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eva.skyman@vgregion.se

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Everyone has the right to be met with respect, always and in every situation.  
Respect, in combination with knowledge and kindness, makes a better world.

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### ABSTRACT

**Aims.** The overall purpose of this thesis was to follow up the consequences of guidelines installed to prevent transmission of MRSA in healthcare from the patients' point of view and subsequent consequences for everyday life.

**Methods.** Patients infected with MRSA during two time-periods were studied. A questionnaire, used in 2004 (n=92) and for a new set of patients in 2011 (n=110) focused on the patients' use and beliefs of a MRSA notification card and their encounters when presenting it in health care institutions. In addition qualitative content analysis of written comments was used (**Study II**). Subsequently, interviews were performed with new subsets of patients to deepen the understanding of the patients' experiences. Six of them infected during hospitalization and source isolated (**Study I**) and 12 infected outside the hospital setting (**Study III**).

**Results.** The findings revealed that MRSA caused humiliation, guilt and anger, and encounters with ignorant staff when seeking health care. Alarmingly, these stigmatizing experiences were more frequent in 2011 than in 2004. These findings were confirmed by the in-depth interviews. The consequences in every-day life contain feelings of being an outsider and refrain from family and friends. The information of how MRSA is transferred was often considered inadequate, sometimes conflicting and a majority were unaware of how they actually acquired MRSA. The patients took responsibility not to infect others, demonstrated in a willingness to show the notification card. Also, isolation, despite described as traumatic, with a feeling of being imprisoned, and having improper rehabilitation, was accepted. However, knowledgeable staff alleviated frustration and the feeling of being an outsider.

**Conclusions.** Patients with MRSA, feel marked and stigmatized due to experiences of fear and unprofessional behavior from staff. Increased education about resistant bacteria and infection control is urgently needed since competent staff reduce patient suffering.

**Keywords:** MRSA, patient, experience, transmission, acquisition, source isolation, ignorance, MRSA notification card

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# SAMMANFATTNING PÅ SVENSKA

## **Att vara smittad med meticillin-resistenta *Staphylococcus aureus* (MRSA). Patienters upplevelser i kontakter med vården och dess konsekvenser i vardagen.**

Avhandlingens övergripande syfte var att undersöka konsekvenserna av införda rutiner för att förhindra smittspridning av MRSA ur patienternas perspektiv samt att undersöka hur smittan och bemötandet i vården påverkar patientens vardag.

Bakterier har en förmåga att utveckla strategier för sin överlevnad som multiresistens. Multiresistenta bakterier (MRB) kan förorsaka svårbehandlade och därmed allvarliga infektioner. Resistenta bakterier ökar alarmerande och utgör ett av de främsta hoten mot vår framtida hälsa enligt WHO. I länder som Sverige, där förekomsten av MRB fortfarande är låg är det viktigt att begränsa deras spridning. Således kontrolleras flertalet enligt smittskyddslagen och inom vården finns riktlinjer om hur dessa patienter ska vårdas för att begränsa smittspridning.

*Staphylococcus aureus* (*S. aureus*) orsakar främst infektioner i hud och mjukdelar som bölder och sårinfektioner men kan också orsaka allvarliga infektioner som blodförgiftning och lunginflammation. En stor del av befolkningen bär dessutom på *S. aureus* som del av sin normalflora t ex i näsan, svalget och på huden. Bärarskap ger sällan upphov till infektioner. Meticillin-resistenta *S. aureus* (MRSA) är multiresistenta *S. aureus* som har utvecklat resistens mot våra mest använda antibiotika. På 90-talet förknippades MRSA främst med infektioner, förvärvade på sjukhus (HA-MRSA) hos multisjuka och äldre patienter. Sedan slutet på 90-talet har MRSA i samhället (CA-MRSA), ökat kraftigt och är numera den dominerande smittvägen i Norden och nu drabbas även yngre personer utan andra underliggande sjukdomar.

Sahlgrenska Universitetssjukhuset drabbades av ett sjukhusövergripande MRSA-utbrott i slutet på 90-talet. Det kunde framgångsrikt bekämpas genom en rad åtgärder som till stora delar fortfarande är i bruk. Åtgärderna har, trots att de används såväl nationellt som internationellt utvärderats i mycket begränsad omfattning. Särskilt patienters upplevelse av de restriktioner som de utsätts för med syfte att minska smittspridning är lite studerat, dvs hur de upplever sin situation som smittade och vilka konsekvenser det får för dem i vardagen.

Patienter smittade under två tidsperioder som omfattade nästan ett decennium studerades. Två grupper av patienterna (2004, n=92 respektive 2011, n=110) fick svara på en enkät (delarbete II). Den fokuserade på det så kallade MRSA-bärarkortet, som patienterna ska uppvisa när de söker vård. Om och hur patienterna använder kortet och deras upplevelser av vårdkontakter kopplade till att vara smittad samt hur de trodde sig vara smittade. De strukturerade frågorna besvarades med ja/nej alternativ och svaren för de två tidsperioderna jämfördes. Patienterna uppmanades även att lämna egna kommentarer vilka analyserades kvalitativt, med innehållsanalys. Enkätsvaren följdes upp med djupintervjuer av ytterligare patientgrupper, dels sex patienter som smittats med MRSA vid vård på Sahlgrenska Universitetssjukhuset i slutet på 90-talet (delarbete I) och därefter isoleringsvårdats samt 12 patienter som smittats med MRSA i samhället på 2000-talet (delarbete III).

Att smittas av MRSA medför konsekvenser för patienten som sträcker sig vida utanför vårdmiljön. I samtliga studier framkom att patienterna känner sig utsatta och stigmatiserade av att bära på en smitta, av några beskrivna som vår tids spetälska. Avsaknad av adekvat och ibland motsägelsefull information om hur MRSA smittar, hur farligt det är och personal som upplevs som okunnig och rädd återkom i samtliga studier tom i ökad omfattning 2011. Erfarenheter av avbruten eller uppskjuten behandling p.g.a. MRSA, okunskap om hur man själv blivit smittad och det bemötande som patienterna utsattes för gjorde att patienterna tog ett mycket stort ansvar att inte smitta andra; ”ingen annan ska behöva uppleva det jag har gjort”. Trots negativa upplevelser visade de i stor utsträckning upp sitt MRSA-bärarkort vid vårdkontakter och accepterade isoleringsvård trots att den upplevdes traumatisk, med en känsla av att vara fångslad och utan kontroll. Smittan påverkade också deras vardagssituation negativt, sannolikt förstärkt av bemötandet i vården. Patienterna lever med en känsla av utanförskap och skam och med en rädsla att smitta familj, vänner och arbetskamrater vilket resulterar i att de avstår från nära umgänge med nära och kära. I alla studierna framhåller patienterna att personal som är van att hantera smittsamma patienter som på Infektionskliniken, påverkar välbefinnandet positivt och lindrar upplevelsen av att vara kränkt och känslan av skam och skuld.

Alla patienter har rätt till ett gott bemötande och sjukvård på lika villkor. Således måste de smittbegränsande åtgärder som vidtas även värderas ur ett patientperspektiv. Vård i isolering bör enbart användas när det verkligen behövs och det fortsatta bruket av MRSA-bärarkortet kan diskuteras. I framtiden måste kunskapen om och förståelsen för resistent bakterier och hur de smittar öka hos alla personalkategorier men även hos allmänheten i stort. Ökade kunskaper och förståelse leder till minskad rädsla till gagn för såväl

patienter som personal och sannolikt även till minskad smittspridning. Det brådskar, om vi ska hålla takt med den allt ökande förekomsten av resistenta bakterier såväl i Sverige som resten av världen.

# LIST OF PAPERS

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

- I. Skyman E, Thunberg Sjöström H, Hellström L. Patients' experiences of being infected with MRSA at a hospital and subsequently source isolated. *Scandinavian Journal of Caring Sciences*, 2010; 24, 101-07.
- II. Skyman E, Bergbom I, Lindahl B, Larsson L, Lindqvist A, Thunberg Sjöström H, Åhrén C. Notification card to alert for methicillin-resistant *Staphylococcus aureus* is stigmatizing from the patient's point of view. *Scandinavian Journal of Infectious diseases*, 2014; 46(6):440-6.
- III. Skyman E, Lindahl B, Bergbom I, Thunberg Sjöström H, Åhrén C. Being met as marked - patient's experiences of being infected with community-acquired MRSA. 2014. (Submitted)

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## ABBREVIATIONS

CA-MRSA	Community associated meticillin-resistant Staphylococcus aureus
CDA	Communicable disease act
CDC	Centers for Disease Control and Prevention
CDU	Local Community Disease Control Unit
EARs-net	European Antimicrobial Resistance Surveillance system
ECDC	European Center for Disease Prevention and Control
ESBL	Extended spectrum beta lactamase
EU	European Union
HA-MRSA	Hospital associated meticillin-resistant Staphylococcus aureus
HCW	Health care worker
MRB	Multi-resistant bacteria
MRSA	Meticillin-resistant Staphylococcus aureus
Strama	Swedish strategic programme against antibiotic resistance
SWEDRES	A report on Swedish Antibiotic Utilization and Resistance in Human
WHO	World Health Organization
VRE	Vancomycin-resistant enterococci





# 1 INTRODUCTION

## Prologue

As a clinical nurse and head nurse for a ten years period during the nineties, at the Clinic of Infectious Diseases, I met a lot of patients infected or colonized with resistant bacteria, at that time, mostly methicillin-resistant *Staphylococcus aureus* (MRSA). Due to an ongoing hospital-wide outbreak great numbers of patients acquired MRSA at the hospital when being treated for another disease.

Patients found positive for MRSA were immediately (within twenty-four hours) transferred to the Clinic of Infectious Diseases. Before transfer they were informed that they hereafter should be treated at the Clinic of Infectious Diseases. Suddenly the patients should leave their departments where they had expert treatment for their illness and be of in a rush from what they often told me was felt to be a safe place. I had the feeling that the information, about this new beyond frightening bacteria they acquired, was given from ignorant professionals. I noticed that patients with MRSA were scared and uninformed at admission to the Clinic of Infectious Diseases. These patients were treated differently to other patients in a lot of situations, for instance surgery and X-rays often became delayed. I often met patients with MRSA who did not get the rehabilitation they were entitled to and were stuck in source isolation at the ward for months as the receiving units would not contribute the admission of them unless they had three negative consecutive screen cultures for MRSA. The cultures were to be taken three weeks after treatment with antibiotics at weekly intervals. This treatment of patients already vulnerable made me deeply frustrated.

One of the most distinctive occurrences was a female patient who stayed at the ward for almost a year. An accidental trauma in her home left her in a bad condition including a huge necrotizing wound at her back head. In a Department at Sahlgrenska University Hospital she acquired MRSA and was moved to the Clinic of Infectious Diseases. Four days after she finally left the ward to stay in a home for elderly people, she died. I will remember her forever. Most patients in the nineties were indirectly infected by the staff at the hospital even if there were some transmission between patients themselves. I wanted to stand up for these patients who were forced to follow routines that included being an outsider and abjected. Some of these routines could later be mentioned as nonsense, non evidence routines. I want to contribute to Infection Control and make all professionals working within hospitals and healthcare facilities aware of the importance of compliance to basic hygiene precautions.

All patients should have the right to be cared for without running the risk of being infected by professionals or health care workers or bullied because they carry a resistant bacteria. So easy and yet not obvious. That is the reason why I became an Infection Control Nurse in the beginning of the millennium. Today, fifteen years later I still come across ignorant professionals afraid of patients infected or colonized with resistant bacteria and I am surprised that there are patients who still do not have the best options for their treatment because they have acquired resistant bacteria.

I was fortunate and do appreciate that I was given the possibility to conduct research and write this thesis as the situation in infection control still demands the need to disseminate knowledge about MRSA and other resistant bacteria. In my thesis I focus on MRSA. However, the knowledge I gained may apply also for other resistant bacteria such as intestinal bacteria producing extended spectrum beta lactamase (ESBL) why these bacteria also are mentioned.

## 1.1 Background

### 1.1.1 MRSA

Bacteria have the ability to obtain strategies for survival why they constitute threats to health and life in those infected. Mostly *Staphylococcus aureus* (*S. aureus*) are associated with boils and skin infections, in derma and soft issues, but principally can causes infections in all organs. Occasionally, these infections could be life-threatening (Grundman *et al.* 2006). *S. aureus* is a ubiquitous bacterium colonizing about 30 % of the general population mostly as asymptomatic carriage (Wertheim *et al.* 2005). Most *S. aureus* can be treated with beta-lactam antibiotics although some *S.aureus* have developed resistance to this group of antibiotics. This type of *S. aureus* is called meticillin-resistant *S. aureus* (MRSA). Infections caused by MRSA could therefore imply a treatment problem. In addition MRSA, can become resistant to additional groups of antibiotics, thus becoming a multi-resistant bacteria (MRB), with few treatment alternatives left (Nathan & Cars 2014).

In the 90ies MRSA was mostly acquired in hospitals, primarily abroad, so called Hospital associated MRSA (HA-MRSA). Since the twenty-first century MRSA has also been associated with infections in the community so called Community associated MRSA (CA-MRSA). The latter has increased substantially both abroad and locally and is now the dominating route of acquisition in the Nordic countries (Skov *et.al* 2005, Stenhem *et al.* 2006, Larsson *et al.* 2014). In general, HA-MRSA is resistant to a number of antibiotics while CA-MRSA is less resistant. CA-MRSA often affect younger and otherwise healthy people presenting boils and wound infections, whereas HA-MRSA cause classical hospital acquired infections and thus affect older people, often with underlying diseases. It is still partly unclear how MRSA in the community is acquired (Weber *et al.* 2005, Grundmann *et al.* 2006). However, acquisition through close skin contact within in the family, in sport activities and between prisoners is described (Johansson *et al.* 2007 Kurkowsky 2007, Lowy *et al.* 2007).

Differences between HA-MRSA and CA-MRSA is suggested to merge more and more and the two types are at occasions hard to distinguish between (Skov & Jensen 2009).

In many parts of the world MRSA constitutes more than 50 % of the invasive *S. aureus* isolates but a decrease is seen in later years in some areas that used to have high rates like United Kingdom and France (Earsnet 2014). In Sweden this rate is presently around 1 %, mostly represented by patients in the

metropolitan areas (Swedres 2013). In Sweden, for epidemiological purpose we also distinguish between domestic acquisition and acquisition abroad (AA-MRSA).

The majority of patients with MRSA are colonized and not infected, often called carriers.

### 1.1.2 Local MRSA epidemiology and infection control

The first patient in our hospital with MRSA infection was found as early as 1983. During the eighties there were few patients with MRSA, since then the number is steadily increasing despite that very few patients are infected in our hospitals (Figure 1). The reason for this increase is that a lot more screening at admission is performed but we also see an increase in community-acquisition both domestically and abroad.

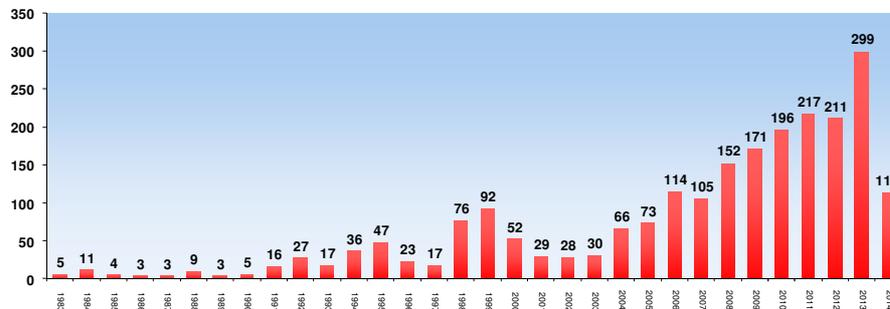


Figure 1. Number of patients detected as MRSA-positive 1983-2014 (September) in the greater Gothenburg area (courtesy Leif Larsson)

Since the very first case the infection control unit has monitored all patients positive for MRSA in the greater Gothenburg area, in close collaboration with the Clinic of Infectious Diseases, the Communicable Disease Control Unit (CDU) and the microbiological laboratory. Every sample has been registered in the microbiological laboratory database and in addition the strains have been examined epidemiologically. For each case the most likely mode of acquisition is determined, irrespective of the reason for obtaining clinical or screen cultures. It is based on this close collaboration gathering clinical data, epidemiological investigation and the laboratory findings, which in many respects make this data base unique.

### 1.1.3 Sahlgrenska University Hospital in numbers

The Sahlgrenska University Hospital is situated in the south western part of Sweden and serves 1,6 million inhabitants. The hospital has approximately 2000 beds and 16700 employees, and offers highly specialized care including pediatric heart surgery, lung-, heart- and liver transplant. There are 1.2 million outpatient visits and 185000 emergency visits on a yearly base. Sahlgrenska University Hospital has 180 out-patient wards and 130 inpatient wards. The laboratories deal with 17000 analyses on a daily base.

### 1.1.4 MRSA routines in the 90´ies previous to the large outbreak

Some minor outbreaks of MRSA occurred in the nineties. They were all eradicated within a limit of time. As soon as a hospitalized patient was found positive, contact tracing started and very quickly additional transmission stopped (Seeberg & Larsson 1997).

All the patients with MRSA were referred to the Clinic of Infectious Diseases. The mean length of stay at the Clinic of Infectious Diseases was very long, forty days between 1992 and 1996, in 1993 even 60 days (Skyman *et al.* 2010). To be able to leave the department and move to for example to an elderly people's home, the patients had to wait for three negative consecutive cultures. If a patient finally became negative another obstacle was to be solved. The health care workers in elderly people's home, were ignorant, frightened and resisted to welcome patients with MRSA. Information at meetings gathering all categories of health care professionals was therefore held continuously. Leif Larsson, hygiene technician, from the Infection Control Unit and myself, at the time working at the Clinic of Infectious Diseases, informed about MRSA and how to proceed and act due to current guidelines.

Many of the routines were made up at the ward at the Clinic of Infectious Diseases with no evidence behind. For instance the patients were treated with chlorhexidine eradication therapy on admission and then continuously every third day. Later the regimen was changed to every fourth day and finally once a week and is now limited to admission. Moreover, any other shampoo, soap or lotion was not allowed to be used, because the effect of chlorhexidine should then be diminished. This was felt as awful for the patients as this treatment makes your skin and hair very dry.

The health care workers always had protective clothes, covering the ordinary dress. The protective clothes consisted of a coat in fabric with long sleeves, a plastic apron, and gloves. This equipment was dressed on every time before

the door was opened into the isolation room irrespective on what purpose the visit had. It seemed to be challenging for the health care workers to comfort to the patients when wearing gloves and a rustling apron whenever touching them. The patients felt uncomfortable to call for someone as they know the time consuming procedure before the entrance to their room. Today basic hygiene precautions are considered sufficient in patient care in Sweden even for these patients.

The equipment including disposable paper, towels, gloves, aprons, clothing, and wound dressings were thrown away from the room when the patient left the ward. In addition all that could be disinfected was processed in a disinfectant and the rest was disinfected with 70 % alcohol based disinfectant. The floor and the toilet/shower room in the patient room was furthermore disinfected by using a toxic and strong smelling disinfectant twice daily, still with the patient in the room.

Instead of being brought to examinations, consultants and radiotherapists visited the patient in the isolation room. When a patient needed surgery, decolonization using chlorhexidine following the pre operating rules was carried out, in addition to the ordinary decolonization regimen. Moreover, Vaseline was smeared all over the patient body to keep the skin flora without flaking during the transportation. Most of the above routines could just be called nonsense routines and are abolished today. Moreover these routines were probably contributing to the patients feeling of being a pest and danger to others, and humiliated. Thus the health care might partly be responsible for patient's negative experiences.

### 1.1.5 Hospital-wide outbreak at the Sahlgrenska University Hospital

A large outbreak of MRSA (E-MRSA 16) at Sahlgrenska University Hospital starting late 1997 and lasting till 2001 included 147 patients and 36 departments (Seeberg *et al.* 2002). In 1998 the spread to the Department of Oncology and the Department of Urology was a fact, it was both care-related and through direct patient to patient contact. In March 1999 the situation was endemic and over 30 departments were involved. Twelve of these departments had minor outbreaks affecting more than two patients. For an increasing number of patients the route of transmission within the hospital was unknown and previous efforts to eliminate outbreaks were found insufficient. The endemic situation was eliminated through several measures taken, intensified routines in close co-operation between the microbiological laboratory, the Clinic of Infectious Diseases and the local Community Disease Control Unit. These resource intensive actions were approved by the hospital board.

Updated guidelines were established in cooperation with the chief medical officer and the responsible physician for MRSA at the Clinic of Infectious Diseases. Most of them are still in practice (Larsson *et al.* 2013) and include:

- Patients hospitalized abroad should be screened for MRSA and awaiting results put in pre-emptive isolation.
- Patients found positive for MRSA and in need of further hospitalization were transferred to the Clinic of Infectious Diseases as soon as possible, preferably within twenty-four hours and cared for in source isolation with designated staff.
- The patients not transferable to the Clinic of Infectious Diseases should be cared for in a single room in source isolation with designated staff. Co-patients in the ward should be screened at a regular basis.
- Patients not in need of hospitalization should be transferred for consultation, information and family contact tracing at the out-patient clinic at the Clinic of Infectious Diseases, preferably within a week.
- Every patient should have a patient responsible physician for MRSA at the Clinic of Infectious Diseases.
- Patients should be informed about regulations according to the Communicable Disease Act (CDA) and given a MRSA notification card.

Most importantly, the patient's medical care should not be prevented or delayed because of MRSA. During the outbreak period readmission screening for MRSA was installed for all patients with MRSA hospitalized at Sahlgrenska University Hospital 1998-2000. MRSA was considered locally as a Notifiable Disease already in 1999, one year earlier than nationally. The infection control unit expanded with three infection control nurses and one physician employed 1999-2000, in addition a two year project consisting of two nurses was launched in 1999 to serve service homes and elderly people's homes.

In addition to the guidelines installed, information lectures about basic hygiene routines, the outbreak and resistant bacteria were held all over Sahlgrenska University Hospital continuously. Brochures and leaflets were compiled to patients and their relatives/friends about MRSA. Moreover, a dress code with short sleeves and no private clothing was demanded in the entire hospital. Basic hygiene routines and official hospital dress codes were non-existent practices in all of Sweden at the time.

The outbreak was considered eradicated in 2000 and just a few patients that belonged to the outbreak were detected in 2001. The total cost to eliminate the outbreak was estimated to be over 2 million € (Björholt & Haglind 2004). Even so the measures taken were estimated to be cost effective.

Despite several of these routines are still in practice, both for MRSA and other MRB in our hospital as well as in the remaining Sweden and in the other Nordic countries, they have rarely been evaluated. Most importantly patient's experiences of the restrictions given to them to limit the spread of the resistant bacteria is sparsely studied.

### **1.1.6 MRSA notification card as alert and being contagious**

Many of the patients infected or colonized with MRSA during the outbreak were old and needed continuous care and subsequently had many hospital readmissions. To identify these patients a MRSA notification card to be used as an alarm system was introduced 1999. An electric alert in the patients' records or hospital data system was not permitted at that time according to the hospital counsel.

The MRSA notification card was to be shown when seeking hospital care, outpatient care or dental care. Showing the card was supposed to guarantee the patients correct antibiotic prescription if needed but also to highlight that the

patient should be cared for in isolation if in need of hospitalization. When the card was introduced in 1999 a decision was made to evaluate the notification card four years later.

Before the outbreak it was practice to declare a patient free from infection after three consecutive negative cultures. During the outbreak it was revealed that despite the negative cultures the patient could still be a carrier of MRSA. Thus, the routine with three negative cultures was abandoned and no patient was to be declared free of MRSA, but instead a potential carrier for life. Information was given to the patient that MRSA could still be colonizing the skin but in small amount not detectable in cultures and that MRSA could “come back” for example if they got a new infected wound or were treated with antibiotics. This message was hard for the patients because they did not know whether they were healthy or ill. Also the health care workers had problems at time to explain all of this to the patients, for instance that a patient was not contagious in everyday life but still had to follow certain rules. The decision at the time was that the patient should be considered as a patient with MRSA for life time, once having a positive culture for MRSA.

## **1.2 National wide regulations**

### **1.2.1 Basic Hygiene Routines**

In 2007 the National Board of Health and Welfare Code of Statutes adopted regulations on basic hygiene in Swedish health service giving responsibility to the health service personnel (National Board of Health and Welfare 2007). These regulations are to limit the risks of health-care associated infections. The importance of health care workers’ compliance to basic hygiene routines to limit the spread for patient safety, is essential and well documented (Ellingson *et al.* 2014). The most common reason for MRSA transmission in hospitals is through contaminated hands (Henderson 2006, Pittet *et al.* 2006, 2009). None the less it is known tha compliance to hand disinfection is poorly carried out by all health care workers (HCWs) and by physicians in particular (Andersson *et al.* 2011, Lee *et al.* 2011). In this thesis physicians are included when the abbreviation HCW is used.

The term Basic Hygiene Routines was invented by infection control nurse Margareta Forsell in Gothenburg in 1999 and replaced the term “barrier precautions”. Basic hygiene routines is a corner stone in infection control. It should always be used and be practiced in all patient care in contrast to barrier precautions that is used occasionally when certain contagions are present.

Basic hygiene routines implies that

- Hands and lower arms shall be free from jewelry and wristwatches.
- Hands shall be disinfected using an alcohol-based hand disinfectant before and after all moments including patient care or examination.
- If hands are visibly soiled or if caring for a patient with gastroenteritis, they shall be washed with liquid soap and water and be dried before the hand disinfection.
- Disposable gloves shall be used in contact with bodily fluids, be aware of transmission with your gloves.
- Gloves are for single use and shall be discarded directly after use followed by hand disinfection.
- Disposable plastic apron as well as visor shall be used if there is a risk for splash or contact with bodily fluids.



*Figure 2. Alcohol based (70 %) hand disinfection. The most important issue to stop transmission is to use alcohol plentiful and rub until hands are dry (courtesy Ingrid Ekfeldt).*

## **1.2.2 Swedish Health and Medical Act**

The Swedish Health and Medical Act 1982 states that providing good quality of care and a high standard of hygiene is a responsibility for all care providers. An additional paragraph in 2006 demands the caregiver to plan and organize the premises and equipment, the staff competence and assure assessment to infection control experts to provide care of good hygienic standard (The Swedish Health and Medical Act 2006). It means that all healthcare providers should have access to infection control expert competence in infection control.

## **1.2.3 Communicable Disease Act**

In Sweden the Communicable Disease Act (CDA) classifies contagious diseases in four groups: notifiable disease, mandatory contact tracing, diseases dangerous to public health and diseases dangerous to society. MRSA became a notifiable disease 2000 which demands the physician who prescribes the culture to notify CDA within 24 hours about the findings. Since July 2004 CDA changed MRSA from being notifiable to be classified as a disease dangerous to the public health. This means that the patients receive restrictions such as the duty to inform about the contagion when seeking care, to obey rules and regulations concerning wounds, catheters and lesions. When classified as a disease dangerous to the public health all screening and contact tracing is out of charge and must be performed (CDA 2014).

## **1.2.4 The National Board of Health and Welfare**

Since June 2010 MRSA could be disclaimed if three negative cultures during a year could be presented. In addition the patient should be free from risk factors such as wounds, lesions, and catheters. This judgement is to be done by the responsible physician at the Clinic of Infectious Diseases. Even so, the patient is still recommended to inform about having been an MRSA carrier when seeking care, to ascertain effective antibiotics in case of need for future treatment (The National Board of Health and Welfare 2010).

### 1.3 The Global Threat of MRSA and preventive actions

The amount of MRB is emerging alarmingly and is today according to the World Health Organization (WHO) one of the biggest threats towards humans in the world. According to the WHO hundreds of millions of people are affected by health-care associated infections (WHO 2011). In this situation resistant bacteria is posing a global threat and causes increased mortality and morbidity related to extensive use of antibiotics. WHO's strategy is to highlight the unnecessary and incorrect use of antibiotics and inappropriate infection control, aiming to slow down emergence of antibiotic resistance (WHO 2014).

The transmission of resistant bacteria is part of resistance development. To reduce the transmission of healthcare associated infections through preventive efforts is therefore vital (Muto *et al.* 2003).

Care for patients with resistant bacteria is steered by the country's economic resources, possibilities to care in isolation and the actual epidemiological situation. Countries with low rates of MRSA often use rigorous and costly routines involving screening cultures and care of patients positive for MRSA in isolation. This strategy is often referred to as "search and destroy" policy, launched in the Netherlands (Vriens *et al.* 2004, Vos *et al.* 2009) and used in the Nordic countries (Skov *et al.* 2005). It focuses on finding patients positive for MRSA at admission (Harbarth *et al.* 2000). Patients hospitalized abroad should be screened at admission and cared for directly in a single room or in source isolation until the results of the screen cultures are present (European Center for Disease Prevention and Control (ECDC) 2011). Positive patients should be cared for in isolation. This strategy minimizes the possibility to transmit MRSA to other patients. Moreover contact tracing and decontamination treatment are involved. Also in high endemic settings admission screening followed by decontamination treatment are becoming increasingly used (Calfee *et al.* 2014).

There are many organizations that fight antibiotic resistance all over the globe and a goal to cooperate regarding antibiotic resistance and similar issues is emerging. Centers for Disease Control and Prevention (CDC), (ECDC), European antimicrobial resistance surveillance net (EARS-Net) and Swedish strategic program against antibiotic resistance (Strama) are some of the organizations working on these matters for future patient safety. The situation in Europe is updated continuously concerning MRSA and other resistant bacteria by EARS-Net and is available on the internet (Figure 3).

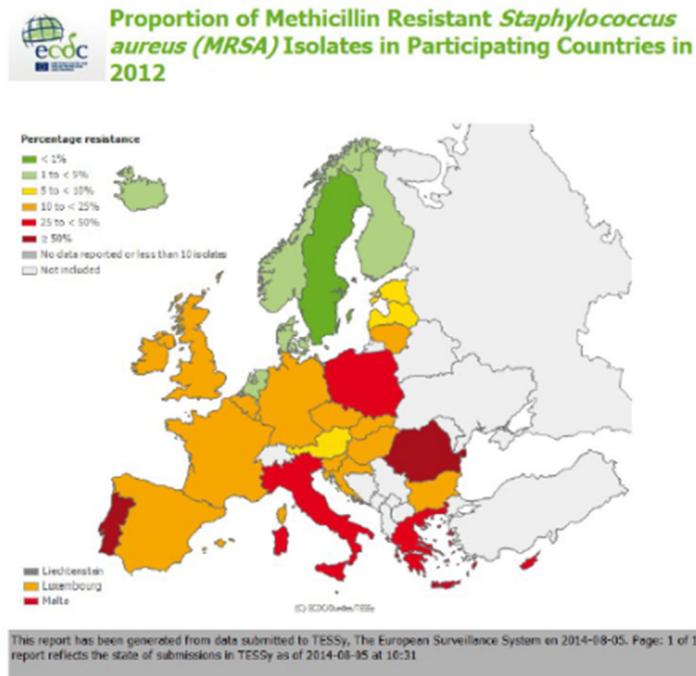
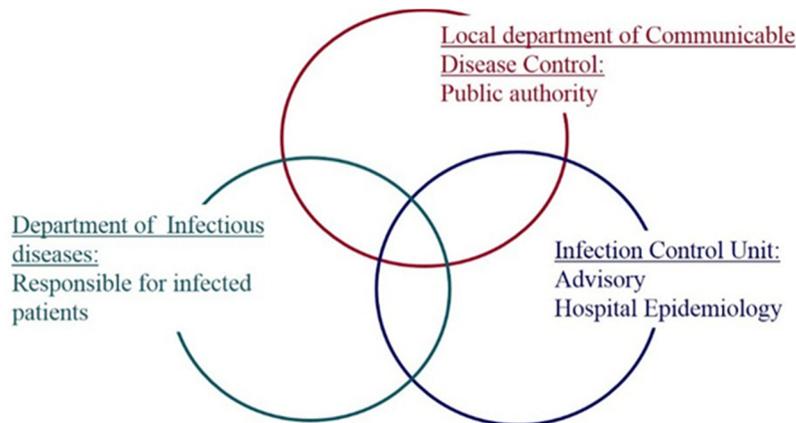


Figure 3. The proportion of methicillin-resistant *Staphylococcus aureus* (MRSA) among invasive *S. aureus* isolates in participating countries in Europe 2012 (as of 2014-10-05, with permission from EARSS).

### 1.3.1 Infection control in Sweden

Sweden has been and still is one of the front-line countries in infection control and prevention. The first infection control nurse (ICN) and infection control physician were employed already in the 1960s in Swedish health care. Since then the staff increased considerably, during the years and in 2014 the numbers of persons working with Infection Control are approximately 125 nurses and 65 physicians and a few hygiene technicians. These persons continue this important work on infection control including patient/staff safety. The work involves issuing guidelines on national, regional as well as local levels. A national association for infection control for professionals within infection control is the Swedish Association for Infection Control and also the Nordic association for Infection Control Nurses, and the Nordic Society of Clinical Microbiology and Infectious Diseases.

Infection control units are located in every County Council and region in Sweden and the work involves epidemiology, education, practical sessions, monitoring incidences of healthcare associated infections, managing outbreaks and drawing up local guidelines on disease prevention and control among other issues. In the Västra Götaland Region many issues are handled through direct interaction with the Infection Control Unit, the Clinic of Infectious Diseases and the local Communicable Disease Control Unit, almost on a daily base (Figure 4).



*Figure 4. Close cooperation and interaction is essential working with contagions and infectious patients.*

## 1.4 Short historical review of “contagion”

Fear of diseases and contagion seem to be as old as human beings. Starting even long before the Bible there are associations between diseases and being unclean. Uncleanliness is linked with bodily fluids, damaged skin or skin diseases. People who were struck with a disease had to face to be left outside, sometimes the individual could be outside a house but also outside the wall of a town to protect the other inhabitants.

In Leviticus verse 13 in the Old Testament in the Bible it is described how to behave if there is suspicion of Leprosy “The leprous person who has the disease shall wear torn clothes and let the hair hang loose, he shall cover his upper lip and cry out; Unclean, Unclean. As long as he has the disease he shall be unclean and live alone. His dwelling shall be outside the camp”.

Historically a disease was often referred to as punishment for having done wrong or evil things, something that is still today in peoples mind when suffering from a contagious disease. During hundreds of years sickness has evoked feelings of fear and horror.

### 1.4.1 Miasma

Miasma was already mentioned in the fourteenth century and kept as a term till the end of the nineteenth century and was used when persons became ill in epidemics (Nohl 2006). It was thought as pollution, bad smells or bad environments with steam, spoilage and ferment and was always associated with poisoned air (Halliday 2001). In the navy, miasma was believed as bringing disease to the ships why it was important to keep them clean. Sometimes ships were fumigated after miasma episodes. However, sickness also evoke interest. It is said that to gain a long healthy life your habitation should be high up and preferably facing south (Hjortsberg 2001).

The contagion theory stated that there was something a person could transmit to another person through bodily contact and the theory became more accepted as the epochal discovery in the end of the nineteenth century became accepted. The history of quarantine however, goes back to the fourteenth century as the Venetian custom of keeping ships from plague stricken countries, were waiting off its port for 40 days. It is the sense of “period a ship suspected of carrying disease is kept in isolation” first enforced at Ragusa late fourteenth century.

Quarantine, originally from Italian “quarantina giorni” which meant isolation for forty days (Harper 2010). Quarantine buildings were built in many places

around the world especially in Europe, America and Australia. Some of them are still preserved. In Sweden four quarantine stations were built: Kängsö, an island in the Gothenburg area, in Stockholm, outside Karlskrona and on Gotland. Kängsö is one of the few quarantine stations well preserved today used by the military force.

### **1.4.2 Florence Nightingale**

Florence Nightingale a nurse and statistician from England stated the contagion theory among others working at the hospital in Scutari with wounded soldiers during the Crimean War in the middle of the nineteenth century. She was a precursor of infection control and practiced hygienic principles such as water supply and sanitary measures, clean air, clean clothes, nourishing food and if possible just one patient in every bed (Nightingale 1859). She treated wounds by using one clean cloth for every patient and by doing so it could be understood that she already knew about cross contamination. Nightingales hygienic principles introduced in the hospital in Scutari made the mortality rate decrease from 40% to 2% among the wounded soldiers.

### **1.4.3 Ignaz Semmelweis**

Another prominent person in infection control, in the middle of the nineteenth century, was Ignaz Semmelweis, a Hungarian obstetrician working in Vienna. He observed the difference in death rates between two delivery departments at the hospital, one managed by midwives and the other managed by doctors. Mortality rates varied by 1,7 % and 17 % respectively. Looking into how the practical delivery work differed, Semmelweis believed that the doctors brought something, a contagion even if yet not described, from the autopsies they examined before the delivery work. He introduced hand hygiene to be performed by the doctors before entering the delivery department (Jarvis 1994, Pittet & Boyce 2001). This simple routine was enough to decrease the mortality to the same level as in the department by midwives. It could be suggested that Semmelweis was the pioneer to prove that hand hygiene between patients makes a difference (Best & Neuhauser 2004). He was, however, considered a fool and put in a mental hospital, while his companion Koletschka was honored of the discovery at the time.

## 2 AIM

The overall purpose was to follow up MRSA culture positive patients personal experiences concerning the consequences of guidelines implemented to prevent transmission of MRSA in health care.

### 2.1 Outline of the Studies

The initial beginning of this project was a questionnaire based examination of the patient's experiences of using the MRSA notification card performed in 2004, as decided when introducing the card. Among other things it showed that patients affected with MRSA had experiences of interactions and encounters within the hospital care that were expressed as traumatic.

**Study I** was initiated by the partial results of the the 2004 questionnaire based study. **Study I** was conducted using indepth interviews and aimed to get a deeper understanding of the patients experiences of having acquired MRSA at the local hospital. Moreover an interesting question was their experiences of subsequently being source isolated.

In **Study II** the same questionnaire from 2004 was used 2011 to examine if there were any changes in experiences concerning the notification card for MRSA over time and in relation to type of acquisition. Also, the patients written comments were anlyzed from both time-periods and compared. As the reported experiences from the questionnaire in 2011 was even more depressing than those in 2004 it was decided to further explore these experiences.

**Study III** was thus performed using indepth interviews focusing patients culture positive for community acquired MRSA.

## 3 METHODS

### **Mixed methodology**

Mixed methodology involving both quantitative and qualitative methodologies are used in **Study II** (Polit & Beck 2012). Combined methods are lately frequently used and the aim of mixed methods is to collect and analyze data, to integrate the findings where after inferences from both quantitative and qualitative research approaches can be drawn (Tashakkori & Creswell 2007). Creswell & Plano Clark (2007) identified that the mixed methods approach is especially suited when the findings by using one approach greatly can be enhanced with the second source of data added. By using mixed methods the limitation of a single approach can be reduced since the involved methods are complimentary representing both words and numbers (Polit & Beck 2012).

### **Content analysis**

The essence of content analysis research in this context is to extract the appropriate data, not to tender generalizations but to make inferences trustworthy and to answer the research questions (Graneheim & Lundman 2004, Polit & Beck 2012). Content analysis provide knowledge and, new insights about textual phenomena and their meaningful uses. It is a research method for making valid and replicable inferences from the data to their context (Krippendorff 2004, 2009).

### **Hermeneutics and phenomenology**

The ontology of Phenomenology is based on the meaning of lived experiences of humans (Ricouer 1976) and rooted in a philosophical tradition. The approach of phenomenology is aiming to understand people's everyday life experience (Polit & Beck 2012). The meaning of the word phenomenon is Greek (phainomenon) and means what is shown or what is revealed (Bengtsson 2005, Ricouer 1981). Ricouer (1991) suggests phenomenology to be developed with the help from hermeneutics to gain a deeper understanding. Hermeneutics is interpretative and was first used by theology's interpretations of the bible. The idea of hermeneutics is to understand what is expressed in a text. Gadamer developed the horizon fusion taken in considering that the reader has his horizon and the text has its horizon and when they merge understanding is created. In other words the parts and the whole merge (Gadamer 1976). The dialectic movement between the two elements is called the hermeneutic circle or the hermeneutic arc (Ricouer 1976, 1991, 1998, Lindseth & Norberg 2004). The role of interpretation is to find the quintessence in the text and open it up and reveal it "the utterance meaning" (Ricouer 1976). It is possible only if the

researcher has pre understanding and knowledge about the phenomenon that should be interpreted. The knowledge must be true and deep to gain a critical approach and not just an opinion. The true knowledge, episteme, is never exalted and you know that you cannot know everything. On the contrary persons with just opinions easily become excited, cannot argue and has mostly problems not to become emotional (Lindseth & Norberg 2004).

### 3.1 Design

This thesis includes three empirical studies (**Study I- III**, Table 1). The design of **Study I** and **III** comprise qualitative data using exploratory design. **Study II** has descriptive and comparative design.

*Table 1. Presented overview of the design of the studies*

<b>Study</b>	<b>Design</b>	<b>Sample</b>	<b>Data collection</b>
I	Exploratory	6 patients locally infected with HA-MRSA during 1998-2001, and source isolated for at least one week	2004; open ended in-depth interviews
II	Descriptive Comparative	Group 2004: 92 patients infected 1999-2003 with MRSA 71 had received a MRSA notification card  Group 2011: 110 patients infected 2008 -2010 with MRSA 91 had received a MRSA notification card	2004; Questionnaire  2011; Questionnaire
III	Exploratory	12 patients infected with CA-MRSA	2011; open ended in-depth interviews

### 3.2 Procedure

The qualitative hermeneutic approach inspired by Kvale used in **Study I** consisted of six in depth interviews and aimed to reveal the meaning of the patients' lived experience of being affected with MRSA. (Kvale 1997). The patients decided where the interviews should take place, all of them choose a room at the Infection Control Unit. The interviews were performed with the

idea that the patients should talk freely and as much as possible. The interviews started by using open ended questions such as “could you please tell me about being infected with MRSA” and “could you tell me how you experienced care in isolation”. Probing also occurred during the interview “how do you mean” or “could you tell me more about this”. The patients themselves could freely decide what they wanted to share and also for how long time. It is not possible to let go of the pre-understanding (Ricoeur 1991, Lindseth & Norberg 2004), instead the importance of the pre-understanding and knowledge about the subject is essential. However, the idea was to interfere as little as possible. It was frustrating not to inform and answer all the patient’s questions during the interview, although it was done afterwards. However, the participating patients were all satisfied to be able to share their experiences with someone listening. Moreover they were offered to read the texts later on, which two of them did.

The phenomenological hermeneutical approach in **Study III** was carried out according to Ricoeur (1976) and as further developed by Lindseth & Norberg (2004). The interviews started by using the identical question as in **Study I** “Could you please tell me about being infected with MRSA”. The interviews differed from **Study I** as probing was more frequent and the questions from the patients were answered during the interview. A mutual interest was shared and the patients appreciated that someone cared and spent time to listen to their experiences. Also, four of the patients preferred to be interviewed in their homes and eight patients choose to be interviewed at the Infection Control Unit. None of the patients were interested in reading the text after the interviews were transcribed verbatim.

### 3.3 Patients

The patients in **Study I** and **Study III** were selected purposively, based on personal judgment about the patients’ willingness to be informative and share experiences (Polit & Beck 2012). In **Study I** six patients, four men and two women (age 35-76 years), were selected by Eva Skyman. In **Study III** the purposive selection of twelve patients, five women and seven men (age 30-66 years), was carried out by Eva Skyman, infection control nurse and Leif Larsson, hygiene technician, both at the Infection Control Unit, Panagiotis Vasilakis, MRSA responsible nurse at the Clinic of Infectious Diseases, and Anne Palmé, infection control nurse at the Infection Control Unit, Södra Älvsborg Hospital, Borås.

In **Study II** a systematic sampling procedure (Polit & Beck 2012) was used. From the laboratory database that includes every MRSA infected patient in the greater Gothenburg area a set of patients were drawn. It included every second

patient, alive at the time, registered culture positive for MRSA for their first time during the respective studied periods (Table 2). No duplicates were included in the cohorts.

*Table 2. Overview of sampling procedure in Study II*

	2004	2011
Total numbers of patients registered culture positive for MRSA	258	418
Sampling procedure	Every second patient (n=129)	Every second patient (n=209)
Total sample of participants	92 (71 %)	110 (53 %)
Sample (patients who had received a notification card)	71	91

The median age in 2004 was 57 years (range 2-87). In 2011 it was 32 years (range 1-83). Six and 16 patients respectively were not yet 18 years old. In 2004, 38% were women, 46 % were men and 16 % responded anonymous while in 2011 the corresponding figures were 49 %, 46 % and 5 % respectively.

## 3.4 Data collection

### 3.4.1 Study I and III

All in depth interviews were carried out by Eva Skyman. Letters with information, written consent to participate and prepaid envelopes were sent to six patients in **Study I** and seventeen patients in **Study III**. All six patients in Study I wanted to be contacted by phone about participation. In **Study III** twelve of the seventeen patients agreed to participate. The interviews lasted approximately between thirty minutes and two hours.

### 3.4.2 Study II

A two part questionnaire was distributed to evaluate the patients use and, to reveal their experiences and opinions of the MRSA notification card. A reminder was sent three weeks later. The questionnaires were colored so that the route of acquisition according to the previous extensive epidemiological investigation could be recorded even for those responding anonymously.

The first part consisted of close ended questions concerning demographic data such as gender, age, believed route of acquisition and moreover if the patients had received a MRSA notification card or not. The second part consisted of questions considering the patients usage and staff reactions when presenting the card. Written comments to the questions were given by 63 % (2004) and 49 % (2011) of the patients that had received a card.

## **3.5 Analysis**

### **3.5.1 Statistics**

In **Study II**, IBM SPSS statistics version 20.0 (IBM corp., Armonk, NY, USA) was used for the statistical analysis. For the comparison of response rates, Pearson Chi-Square test Crosstabs were used and  $p < 0.05$  were considered significant.

### **3.5.2 Data analysis**

#### **Study I and III**

The interviews were tape-recorded and then written down verbatim. Emotional expressions such as crying, laughter, sighs and similar were included into the text. The text was read several times in order to get an idea of what the text as a whole was about. The authors' previous and long experiences from caring of patients with MRSA and knowledge of MRSA, thus greatly aided the interpretation processes.

In **Study I** an intersubjective approach was carried out by two of the authors who analyzed the text independently to increase reliability and validity of the results (Kvale 2009, Polit & Beck 2012). The transcriptions were read several times, and significant statements were coded separately. To achieve an analytical framework, the codes were categorized and two of the authors proposed and discussed the coded categories until agreement was obtained. Finally, seven categories were constituted as the essence of the interviews.

#### **Study II**

The comments given in the questionnaire were written down to a text that was read and reread many times to obtain a sense of the whole and to ensure that the first impression was corresponding to the research question (Krippendorff 1991, 2004). The aim was to focus on the context in order to find and resemblance similarities and differences why the following step was to extract meaning units and group them. The meaning units were subsequently coded

and regrouped into subcategories to create the final categories as in accordance with the analyze process of Graneheim and Lundman (2004). Their suggestion is to build a theme or several themes to constitute the findings. We choose to keep the category for describing the phenomena why there are no themes in this study. Manifest as well as latent content analysis was used, so that the text could be additionally interpreted.

In **Study III** a structural analysis was conducted in accordance with Lindseth & Norberg (2004). As a text is dependent on the lived experiences of the researcher's life world (Gadamer 1976, Ricoeur 1976) the text was read and reread many times until agreement on naive understanding was obtained. This subjective phase moved the researchers both by content and meaning within the text. The naive understanding invited us into the structural analysis. In this step the text was organized into meaning units with similar or related content which were condensed thematically. The structural analysis was carried out as we moved from what the text says to what the text talks about in a dialectic movement from the parts to the whole and from the whole to the parts (Ricoeur 1976, 1991). Brought together the interpreted whole, the naive understanding, the structural analysis and the author's pre-understanding provided new, deeper comprehension of the patients possible existence in the world. It revealed, for these patients how everyday life manifests itself being infected with MRSA (Ricoeur 1976, 1991, Lindseth & Norberg 2004).

## 4 ETHICAL CONSIDERATIONS

The studies was approved by the Regional Ethical Review Board in Gothenburg, Sweden.

In **Study I** and **III** the patients were informed both verbally and in writings that their identity would not be disclosed and that they could withdraw their participation from the study, at any time without any consequences concerning their contacts with the healthcare system. The patients signed a written consent. In **Study II** the information was given in writing together with the questionnaire. The consent was given from the patients by choosing to answer, the questionnaire and they were free to give their name or to be anonymous.

Written agreement is obtained from the Editorial Offices concerning the articles.

## 5 RESULTS

Facing patients with MRSA reveals ignorance, and seems to lead to unprofessional encounter and behavior within all categories of personnel working in health care. In particular those not accustomed to care for patients with MRSA. The patients' described their frightfulness and being out of control and also a feeling of being an outsider and as pest. These results were a consistent finding throughout all the studies. The early infected patients (**Study I** and **II**) revealed that they did what they were told to do. They were prone to feel uncertainty and offence. The more lately infected patients (**Study II** and **III**) seemed to question why they should act or be treated in a special order and described anger and discrimination. Moreover the acting from professionals gave wider circles and the patients did not feel that they gained the same rehabilitation and treatment that patients free from resistant bacteria do. Despite their endurance the patients took great responsibility not to infect others (**Study I, II** and **III**).

The findings in the three studies are presented in following structure.

### 5.1 Inadequate behavior resting on professionals' ignorance

**Study I** and partly in **Study II**, describe the situation when a hospitalized patient became culture positive for MRSA and the sample result reached the HCW at the department where the culture was obtained. The responsible physician was to inform the patient about the findings. The patients were met by frightened professionals in the ward who were distancing themselves physically from the patient. The HCWs were eager to transfer them to the Clinic of Infectious Diseases as quick as possible irrespective of the patient's underlying illness.

Patients in **Study III** and partly in **Study II** who did not need hospitalization, were not directly transferred to the out-patient clinic at the Clinic of Infectious Diseases. Most of them were detected in the out-patient settings and were remitted for information, and treatment if needed, and were seen about a week later. As the patients lacked information about MRSA they downloaded information from internet, and they were also willing to inform the nurses and physicians (**Study III**) in order to protect their co-patients. Thus, the information given about MRSA and the consequences it led to was shown to be insufficient from the patients' point of view, at this preliminary stage (**Study I-III**).

Furthermore the patients described they felt that they became victims as they acquired MRSA in the hospital through no personal fault. The patients noticed that hygiene precautions were not adequate and that there were sloppy behaviors for instance treating wounds with a long sleeved cardigan (**Study I**). On the contrary there were patients who experienced overdressed health care workers, looking like astronauts but also patients who experienced that protecting clothes were not used at all (**Study II & III**)

However, knowledgeable professionals at the Clinic of Infectious Diseases were alleviating the experience of being contagious and as pest and were moreover described as calming ‘everything down’ giving good and trustful information and treatment. In contact with knowledgeable professionals the patients experienced that their dignity was perceived. (**Study I-III**).

## 5.2 Use of the MRSA notification card

The majority of patients showed the notification card when seeking hospital or outpatient care although showing the notification card at the dentists increased significantly in the 2011 group (**Study II**). However, one patient in **Study I** revealed that the card was confusing and was uncertain if the card should be used when having negative cultures. The patients felt pointed out in a negative way by given a notification card but none the less, most were still willing to show it with the aim to protect co-patients. Showing the card at the reception was met by both familiar recognition from the health care workers as well as fear (**Study II**). Three out of 71 patients actively stated that they felt uncomfortable to show the card when seeking hospital or outpatient care in 2004. This number increased to 13/91 patients in 2011.

## 5.3 Perceived routes of acquisition

**Study I** reveals that some of the patients were aware of bad compliance to hand hygiene and precautions why they thought MRSA were acquired at the hospital both in 2004 and 2011. The result of perceived routes of acquisition in relation to documented routes from the epidemiological investigation showed that misconception was in majority and also that unawareness increased in 2011 in comparison to 2004. It was rarely believed both in 2004 and 2011 that MRSA were community acquired.

## 5.4 Consequences of being contagious

Experiences of being contagious varied from not being affected at all to feel as plague afflicted (**Study I-III**), distaste and abject (**Study III**). The patients kept away from social contacts like friends or family, not to risk spreading MRSA but also because they felt guilt and shame about their condition (**Study I & II**). To pass over resistant bacteria to grandchildren was experienced as dreadful why the patients decided to avoid kissing or touching them (**Study I & III**). It was also stated that friends chose to break the relation because they became afraid of getting infected with MRSA themselves (**Study III**). Phenomena like being violated, unclean and guilty was expressed and furthermore the feeling of being totally abandoned (**Study I**).

## 5.5 Consequences of care in isolation

In **Study I** the consequences of care in isolation was described. It was experienced as very hard by the patients. Most patients were isolated for several weeks or even months. To be kept from your fellow patients and to have to stay in the room was described as to be out of control, in prison and as pest (**Study I**). In addition the patients felt bored as they did not get any spontaneous visits from the health care workers and had to eat their meals in the room. Moreover to be cared for in isolation was frightening because the patients realized that they themselves were considered a danger to other patients (**Study I**). In contrast some patients appreciated to have a single room (**Study I & II**) and most patients appreciated to see the nice park and the greenery outside the windows of the ward.

The patients were aware of their position as outsiders compared to others as they could not leave for other departments for a long time due to MRSA screen samples (**Study I**).

## 5.6 Consequences of everyday life

The patients felt upset to generate fear in the surroundings, which in addition evoked feelings of being unwelcome (**Study I-III**). Loss of dignity was moreover outspoken and also a feeling of being stigmatized (**Study I-III**). All three studies revealed that living with MRSA meant to be treated different from others in respect of rehabilitation and treatment. In **Study I** the patients said they were denied proper and timely care due to MRSA, exemplified by lack of stroke rehabilitation and interrupted and postponed surgery due to cancer (**Study I**). The patients stated they were forced to be the last patient of the day

and not be allowed to sit in the out-patient reception because of resistant bacteria (**Study III**). **Study II** revealed that a patient had to wait outside an emergency department, on the street, for fifty minutes. Being bullied by both private peers and colleagues was experienced as very hard. It seemed that the patients had to be the informant about MRSA transmission to health care workers as the health care workers asked how they should behave to avoid transmission of MRSA themselves (**Study III**).

## 5.7 Comparing results regarding acquisition, interactions and information

Apart from the negative experiences, knowledgeable staff at the Clinic of Infectious Diseases were mentioned as professional in all studies and information given was experienced as good and sufficient. A striking similarity in citations was found throughout the studies as shown in Table 3.

*Table 3. An overview of some of the comments from the patients during the ten year study period.*

### Comments on having acquired MRSA

Study 1	Study II	Study II	Study III
I feel radioactive Am I bringing this to heaven?	I feel like plague smitten	It is like pest horrible.	It is like having leprosy.

### Comments on interactions with health care

Study I	Study II	Study II	Study III
They (HCWs) diminished me and I was just MRSA.	The health care workers offended me.	They violated me, I cried because I was not welcomed anywhere, I lost my dignity.	Some acted hysterically. Do they even think of me as a person?

**Comments on rehabilitation and surgery**

<b>Study I</b>	<b>Study II</b>	<b>Study II</b>	<b>Study III</b>
I did not get one hour rehabilitation after my leg surgery, not one.	I was sent home from elected surgery without any information except that I had MRSA.	My treatment was interrupted.	I had to wait for a long time before I got my foot surgery.

**Comments on information**

<b>Study I</b>	<b>Study II</b>	<b>Study II</b>	<b>Study III</b>
There was a lot of mixed messages.	I did not get any information at all.	I wanted much more information.	I found the information at internet.

The results on information were somewhat different in 2014 compared to previously, as the internet was used for information about MRSA in 2014 (**Study III**).

## 6 DISCUSSION

The ancient principle of Hippocrates was to do no harm “*primum nil nocere*” a term that still is valid in medicine and caring disciplines. It could definitely be related to compliance to basic hygiene routines referring not to pass over any contagion bacteria or virus to any patient. To do well is the most important issue healthcare workers all categories have when meeting patients. I am convinced that this is the intention for everyone working in the health care sector. There are however, situations affecting the HCW’s professional behavior. Lack of knowledge about resistant bacteria, MRSA in particular, seems to affect health care workers in the sense that they lose their professional behavior.

### 6.1 Lost professionalism

It seems that the underlying reason for loosing professional behavior is ignorance resulting in fear. Lack of knowledge about microbes and how they spread makes MRSA and other resistant bacteria frightening to face. Nurses and physicians appear uncertain about how to protect themselves and what kind of hygiene precautions that should be taken to avoid transmission. This uncertainty is very hard to hide from the patients. They describe that the professional’s eyes disclose fear when meeting them. The professional’s ignorance is also the root of the problem regarding lack of adequate or wrong and conflicting information, given to the patients. Even no information at all were described. It is obvious that it is difficult to pass over information if knowledge about the current subject is missing. It is also important to know that patients culture-positive for MRSA generally have very poor knowledge about antibiotic resistance prior their acquisition (Rodhe & Ross-Gordon 2012).

During the ten year period that covers this thesis, unfortunately very little has changed in these matters. I believe that information about resistant bacteria has been quite frequent in media and also professionally to HCW and anticipated to find higher rate of understanding today, especially among professionals. However, I was wrong and the fear and ignorance seem to be as common today as it has been during the last two decades. The presentation in media in UK has according to Gould *et al.* (2009) been sensational and inaccurate about MRSA and resistant bacteria. As many as 454 articles revealed MRSA or superbug in the headlines in UK during three months in 2005 (Gill *et al.* 2006). A majority of participating patients in a study in UK had heard of MRSA mainly via media and thus would feel either angry or afraid if they acquired MRSA (Hamour *et*

*al.* 2003). Since WHO claimed resistant bacteria to be the number one threat to human health the information in media has increased in Sweden, especially through initiatives from CDA and Strama. This information could possibly be hard to understand among the public but ought to be understood by nurses and physicians. However, the impact seems to be greater with tabloids sometimes presenting scaring and unserious messages such as “your handbag is full of superbugs” or “the screen on you mobile telephone is crowded with dangerous superbugs”. If knowledge among HCWs is leaning on such information it will be shown when meeting patient positive for resistant bacteria. However, it is demanding for healthcare professionals to be updated about all the various matters that affect their profession, especially matters they rarely encounter.

## 6.2 The MRSA notification card

In the end of the nineties during the large outbreak at Sahlgrenska University Hospital it became clear that the patients who acquired MRSA at the hospital often had severe diseases why they were frequently readmitted and that some type of alert was necessary. The importance of alert, mostly electronic alert, for MRB has subsequently been highlighted (Pittet *et al.* 1996, Kac *et al.* 2007, Kho *et al.* 2008). Different alarm systems were discussed at the time and it was decided to introduce the MRSA notification card. Its use has however, never been evaluated despite subsequently introduced throughout the Nordic countries.

The literature does not cover studies on notification cards for MRB. Thus there were no existing studies or questionnaires matching our framing questions, so we had to compile a questionnaire of our own to evaluate the use of the card. Compiling a questionnaire is generally argued to be very difficult, and we can only agree. However, we chose to keep the concept over time to enable comparison.

It could be argued that the questionnaire was weak and that the questions could have been formulated and put otherwise. However, our knowledge of daily handling matters concerning MRSA-infected patients and previous experiences of care and close contact with these patients greatly aided and made us well aware of their situation. We could thus, form the questions based on our previous knowledge on MRSA to get, as we believe, reliable information about their experiences.

Considering the time laps between the two questionnaire periods, around seven years, we were surprised that the experiences and the answers did not differ more. We had anticipated that the situation had changed to the better over time.

Today there is a development towards electric alarm about resistant bacteria in the patient records. However, the outpatient settings and entailed settings are still not included in this system, which make it incomplete.

The perceptions or rather misconception about routes of acquisition is interesting in a country with a low rate of MRSA such as Sweden and low rate of, if any hospital transmission. This can have several explanations. If the patient's experience sloppy behavior from the HCW as described in **Study I** and lack of compliance to basic hygiene precautions is highlighted in media, as in recent years, this of course make them prone to believe that transmission occurred in the hospital setting. Also, at several occasions the sample was obtained during hospitalization, but the epidemiological investigation revealed another route of transmission, however not forwarded to the patient or the doctor in charge. Thirdly, all patients are asked at admission if they have had any visits to a hospital abroad which is considered a major risk for being positive for MRSA. If so, the patients are screened. This of course highlights hospitalization as a risk for the patients.

The most appalling finding is the patients' willingness to present the card despite their endurances when presenting it. The patients took great responsibility and showed the notification card with the aim to protect fellow patients. Even if the MRSA notification card at first site seemed to be positive for the patients. The qualitative analyses showed that the positive attitude was to protect others from the contagion and that they did not want anyone to be in the same unwanted position as themselves (**Study II**). Also Lindberg *et al.* (2009) found that patients felt forced to show the card and questioned the openness they had to endure in contact with healthcare services. Several patients stated that the card was unnecessary and that they themselves could inform about their carriership. Considering the high willingness to inform the HCW and protect others one may debate the existence and forced use of the card.

### **6.3 Source isolation contra protective isolation**

The term source isolation is used when a patient is infectious or contagious and should be cared for separated from other patients who they can endanger. Protective isolation is used for the opposite purpose to protect the patient from others, for example when a patient is preparing for a bone marrow transplant and chemotherapy (Campbell 1999, Cohen *et al.* 2001).

Patients in protective isolation are in contrast to those in source isolation, well informed and are cautious about having as few visits as possible because a visit could result in postponed treatment i.e. transplantation (Campbell 1999). They don't feel anger and imprisoned to the same extent as patients in source isolation. Nor are they seen as danger to others, including HCW. It is thus suggested that patients should be prepared for care in source isolation to decrease their anxiety and anger (Catalano *et al.* 2003). This is very hard to practice in reality as the patients are moved into isolation as quick as possible when a culture is found positive for the MRB in question. Having acquired MRSA or other contagious diseases that need to be cared for in source isolation rarely is a situation that one is prepared for.

## 6.4 Source isolation

Isolating patients is common practice in most hospitals to control and minimize the spread of MRSA and other resistant bacteria but also other contagions (Gastmeier *et al.* 2004). Care in isolation awake feelings of being dangerous to other people, as plague smitten and dirty which is exaggerated by the use of protective clothing (Madeo 2003, Knowles 1993, Lindberg *et al.* 2009). This is in accordance with this thesis witness about being encountered with health care professionals dressed like astronauts (**Study III**). The need for health care professionals to know how feelings that occur in source isolation care could be relieved and alleviated is extremely important and urgent. Already twenty years ago Horton (1993) claimed that staff's poor knowledge of micro-organisms and infection control practices lead to unnecessarily complicated isolation precautions. Being a nurse at the Clinic of Infectious Diseases at that time I could not agree more. It often happened that professionals driving the ambulance were overdressed and asked for disinfectants to use after the patient was moved into the clinic.

Healthcare workers are half as likely to enter the rooms of patients in source isolation (Tarzi *et al.* 2001, Stelfox *et al.* 2003, Morgan *et al.* 2011), but compliance to hand hygiene are more likely to be done after caring for them than after caring for patients not in isolation (Kirkland 1999). Kirkland also argued that physicians in particular are bad to perform hand hygiene, in just two of 12 contacts with patients hand hygiene was carried out. I will always claim that failures regarding hand hygiene is one major reason MRSA is spread in hospitals and entailed settings. Barratt *et al.* (2011) is describing the patient's experience of isolation as "behind barriers" with impacts on the delivery of quality care but also impact on the provision of emotional care. In accordance with this thesis source isolation due to MRSA is described by

Madeo (2003), and Robertsson (2004) as segregation from other patients, loneliness and fewer visitors and may contribute to feelings of abandonment and less interactions with staff. The feeling of being imprisoned is discussed by Braut and Holt (2011) as well as MRSA as the infectious stigma of our time. The findings of source isolation in the thesis are consistent with previous studies why the transferability is suggested to be accurate. I believe that this feelings also could be transferable to relatives or other close persons who are the side of a very ill patient in the intensive care unit (ICU), as described by Olausson *et al.* (2014). She claims that lack of stimuli in an ICU room creates a feeling of being disconnected from the world like being in exile from ordinary life.

### **Stigma**

Stigma has been defined as a perception that discredits and damage the identity of those affected (Hinshaw 2007). According to Stuber & Schlesinger (2006) stigma could be distinguished between two types, namely identity stigma and treatment stigma. The identity stigma refers to concerns about being negatively labeled, whereas treatment stigma refers to the expectations of poor treatment by others. In this thesis both types of stigma were identified.

The patients in all three studies forward a feeling of being stigmatized not only by having to present the notification card but being seen as contagious. They describe situations when having to be the last patient of the day in radiotherapy, the outpatient clinic and additionally not welcome to sit in the common waiting room. Furthermore to get improper rehabilitation and have surgery postponed was felt stigmatizing. Also the use of protective clothing by the staff were felt stigmatizing as well as not being touched by HCW.

## **6.5 Consequences of being contagious and everyday life**

There is a broad and rich variation of how the patients reacted to the message of being positive for MRSA and the consequences it caused not only when seeking health care but also in everyday life. It is remarkable finding that health care workers of all categories due to ignorance unintentionally make patients suffer instead of relieving the patient suffering. **Study I** revealed that feelings of shame, guilt and being dirty was paralyzing and a major concern (**Study I** and **III**), similar to what has been discussed by Lindberg *et al.* (2009). She is arguing that HIV patients could have the same feeling of dirtiness and threat to others. According to Washer *et al.* (2008) MRSA was associated not only to dirt but also “bad air” in hospitals like the old miasma theory. Being infected

with MRSA is also described as having the twenty-first century lepers (Mozzillo *et al.* 2010, Braut & Holt 2011). This is comparable to our findings as being discriminated from your legal rights but also from friends and in addition a feeling of having the leprosy or pest. Andersson *et al.* (2011) claimed that patients with MRSA compare it with having the plague or leprosy and moreover they felt guilt and shame. Patients, culture positive for ESBL experienced a feeling of pest and guilt and also unprofessional behaviour from health care workers (Wiklund *et al.* 2013). Andersson (2011) also noted that the patients had fear to mention their infection for fear of being rejected. It could be argued that the numerous similar statements are remarkable and that the result is shameful to all professional healthcare workers.

Moreover decisions about if it could be safe to meet and hug grandchildren was hard to take, feeling guilty if they would be victims as well. This is in accordance with Hill *et al.* (2013), who discussed questions put from patients as well as caregivers, such as “can I kiss my husband” and a physician said “on some level you can answer those questions, but most of them (related to transmission) are hard, we don’t know”. I claim that healthcare professionals should be able to answer these questions and be able to alleviate the patients suffer.

The three studies in this thesis give witness about the responsibility the patients took not to risk transmission to anyone. Some of them would rather keep away from dinners and celebrations to feel safe not to transmit MRSA. At the hospital or other health care settings they informed about MRSA and showed the notification card even if some were rejected and had to wait outside.

The somewhat mixed messages the patients were given made the risk of transmission even harder to understand. Being isolated and not allowed to sit in a waiting room because of contagiousness and at the same time be given the message that it was all right to be close to relatives, and go home by public transportations was indeed conflicting.

The patients were angry and surprised that they no longer seemed to have the same rights as other patients concerning rehabilitation and surgery (**Study I-III**). The guidelines at the actual time period were very clear on these matters and highlighted that patients should never be delayed or denied treatment because of MRSA. Unfortunately, this happened to a lot of patients.

## 6.6 Methodological considerations

### Mixed methods

The strengths in this thesis were the use of both qualitative (**Study I-III**) and quantitative methods mixed with a qualitative (**Study II**) method. By using mixed methods the patient's experiences and opinions behind the numbers were revealed and thus complementary to the quantitative approach. An overarching goal in mixed studies is to achieve both discovery and verification which clearly is shown in **Study II**. It is in accordance with Polit & Beck (2012) describing both words and numbers being the fundamental languages of human communication.

The qualitative research questions in this thesis concerned experiences and feelings while the quantitative research questions instead involved descriptive prevalence. The qualitative research thus helped us to explain the quantitative results that sometimes were difficult to interpret. In this way mixed methods allowed us to do what was best and we possibly avoided the limitations of a single approach (**Study II**).

In **Study II** we used content analysis with the aim of making replicable and valid inferences of data to their context and with the purpose to provide knowledge, a representation of facts and new insights and additionally broadly describe the phenomenon (Graneheim & Lundman 2004, Elo 2007). In the field of research, content analysis has found its critics but regardless of the criticism content analysis offers researchers major benefits such as content sensitive and flexibility both to understand the meaning of communication and to identify critical actions regarding to Krippendorff (2009).

By using qualitative approach in research concepts of credibility, transparency, trustworthiness and validity could be required (Graneheim & Lundman 2004). These words and their implications are described in a numerous qualitative research, books and articles. However, sometimes hard to alter and be distinguish about.

As most of the patients shared their experiences and opinions freely and generously the body of text became voluminous (**Study I and III**). By having an open dialog and a critical reflection regarding the body of text, including co-researchers and experts in the field the credibility, as referring to the confidence in the truth of the data and the interpretations of them, was strengthened (Whittemore *et al.* 2001). The body of text and stability in data over time demonstrates dependability (Guba & Lincoln 1994). Regarding the integrity, the subjectivity may be unique and was evidenced in the process to

assure that the interpretation is valid and grounded within the data (Whittemore *et al.* 2001). It could be argued that our studies might have limitations concerning small populations in **Study I** and **III**, a larger size might have strengthened the results but taking previous studies that disclosed similar findings into consideration we believe we achieved credibility (Newton *et al.* 2001, Lindberg *et al.* 2009, and Andersson *et al.* 2011). It is striking that there are so many similarities in the patients' experiences and behaviors. Also the findings were stable over time thus contributing to trustworthiness. It could also be argued that the questionnaire was weak and that the questions could have been formulated and put otherwise. However, we chose to keep the concept over time in the sake of validity and reliability.

## 7 CONCLUSION

There are huge problems to deal with in the context of MRB all over the world, in this thesis illustrated by MRSA affected patients in a low grade endemic setting. It is appalling that all three studies covering almost a decade during a period of changing MRSA epidemiology gave such similar results of the patient's experiences of MRSA, their encounters with health care as well as in their daily life. One may wonder if we have learnt nothing.

Acquiring MRSA appear to truly change the life world from the patients' perspective. The patients with MRSA are vulnerable and feel stigmatized. The lack of adequate information and sometimes withheld treatment and experiences of fear, disrespect, lack of knowledge, and unprofessional and sometimes frightened behavior from the health care workers puts further burden on the patients, extending way beyond the health care setting. The patients take great responsibility not to infect others which affects their everyday life negatively as they live with fear and the feeling of being an outsider. However, knowledgeable professionals accustomed to contagious and infected patients as those at the Clinic of Infectious Diseases were said to alleviate the patients' suffering.

All three studies clearly show that the interactions between the patients and all categories of health care workers must be improved. There is a need for increased education in infection control and how contagions like MRSA are spread. This will not only reduce transmission but most importantly will result in trustful relationships between patients and health care workers so that the patients' dignity can be preserved and their fears relieved. An increased general knowledge and understanding of how microorganisms are transmitted and how prevention can be installed in everyday work and life will hopefully reduce the fear of these pathogens as well as their actual transmission. From the view of the affected patient we only hope that the future need for guidelines affecting the patients negatively like the notification card and isolation procedures described in these studies, will be reduced.

## 8 FUTURE PERSPECTIVES

The situation patients with MRSA faced the last decade is not acceptable and must be improved. Emerge about the spread of antibiotic resistant bacteria in a global perspective ought to affect everyone to take responsibility and be informed. This could not be put on the patient's shoulders when being vulnerable and seeking care. Patients have the right to be treated correctly and to have good interactions with professionals in health care settings, retaining their dignity irrespective if they are carrier of a contagion or not. Increased knowledge about how bacteria spread and behave and how to protect oneself and the patients from resistant bacteria is an important step to achieve this goal. Increased knowledge will hopefully make the health care workers feel safe and secure in their encounters with infected patients.

Considering the speed of the increasing prevalence of MRB the need of a better educational level in all health care professionals is urgent. In the future most health care workers will have to handle patients carrying resistant bacteria more or less on a daily basis, not only those working in the Clinic of Infectious Diseases. This will require large educational efforts, not only in general infection control and how to perform basic hygiene routines and the importance of consistently keep compliance on a high level but also in assessing the risk of transmission from an infected patient. To meet this challenge more infection control nurses and physicians are needed.

For the sake of the patient, care in isolation should be minimized as much as possible. To aid in this matter it is crucial to make risk assessments for every case repeatedly, in order not to isolate all patients with multiresistant bacteria but to isolate those who are at risk of transmission. With an increasing number of single rooms with hygiene facilities in each room, as in most newly built hospitals, source isolation will be less necessary and will hopefully not appear as stigmatizing as now. However, the effect of single rooms will only be valid as long as basic hygiene routines are followed.

We believe that the present use of the MRSA notification card, forcing the patient to show it when seeking care, is questionable. The patients were found very willing to inform about their carriership and can and will do so verbally. Electronic alerts on MRB are increasingly introduced in the hospital setting so that the patient him- or herself is not the first to inform and face the immediate reaction to their carriage of resistant bacteria. But until we have communicating records in all health care there will still be situations with a need of information from the patient.

At the Institution of Health and Caring Sciences the lecture hours in infection control and resistant bacteria have increased from 3 to 12 hours during this ten year period throughout the three years education program. The knowledge among nurses is thus increasing and there is certainly a challenge for the educational program of medical students to follow. Information about resistant bacteria and infection control from the infection control unit together with extended knowledge in caring and medical programs will hopefully make a great difference in the future. This said with great respect to our precursors hundred and fifty years ago, Florence Nightingale who was present for the patients and kept their dignity and Ignaz Semmelweiss who advocated hand hygiene.

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