Awareness of Infection Control within Cystic Fibrosis Health Care – a Scandinavian study

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Master of Public Health

MPH 2013:6

norden

Nordic School of Public Health
NHV

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ISSN 1104-5701
ISBN 978-91-86739-62-1

Nordic School of Public Health
NHV

MPH 2013:6
Dnr U12/06:362

Master of Public Health

– Examensarbete –

Examensarbetets titel och undertitel				
Awareness of Infection Control within Cystic Fibrosis Health Care – a Scandinavian study				
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Författarens befattning och adress Autoriserat sykepleier/klinisk spesialist i sykepleie Norsk senter for cystisk fibrose, Oslo Universitetssykehus HF, Ullevål sykehus, Postboks 4956 Nydalen, 0424 Oslo				
Datum då examensarbetet godkändes 13.12.2013		Handledare NHV/Extern Marita Gilljam, MD/PhD		
Antal sidor 67	Språk – examensarbete Engelsk	Språk – sammanfattning Norsk	ISSN-nummer 1104-5701	ISBN-nummer 978-91-86739-62-1

Hensikt: Studiens hensikt var å belyse etterlevelse av regimer for hygiene og infeksjonskontroll innen cystisk fibrose (CF) omsorg ved de seks skandinaviske CF sentrene (SCFC) og ti norske CF satelitt team (NCFST).
Metode: Individuelle spørreskjema ble distribuert til seks SCFC og ti NCFST. Spørreskjemaet var tilpasset fra en tidligere Knowledge, Attitude and Practice (KAP) spørreundersøkelse for helsepersonell innen CF og smittevern i USA med spørsmål angående ekspektoratprøver, håndhygiene, opplæring og tiltak for infeksjonskontroll i sykehus og hjemme. Etterlevelse >75% for alle komponenter var vurdert som tilfredsstillende i klinisk praksis.
Resultat: Det var 61 (37 %) respondenter fra SCFC, og 30 (58 %) fra NSCFT, hovedsakelig leger, sykepleiere og fysioterapeuter. SCFC har flere ulike profesjoner med ulike erfaringer fra klinisk virksomhet, og respondentene viser et høyt KAP nivå på de fleste komponenter av undersøkelsen (100-49%). NCFST representerer kjerneteamprofesjoner, og respondentene viser moderat til høyt nivå av KAP på de fleste komponenter ved anbefalinger og undersøkelsen (100-23 %). Et nøkkelfunn var det høye nivå av forventet resultat hos begge studiegrupper for alle utvalgte komponenter av undersøkelsen (100 - 80%), i kontrast til et mer moderat nivå av kunnskap om anbefalingene. Tiltak med nær tilknytning til klinisk praksis og medisinsk behandling viste høyere grad av etterlevelse hos begge grupper (73 % og 80 %, 93 % og 74 %), mens kunnskap om innhold i skriftlige anbefalinger var lavere (49 % og 23 %).
Konklusjon: Infeksjonskontroll er en hjørnestein i CF behandling, og betydningen av helsepersonells etterlevelse av anbefalinger for CF infeksjonskontroll er essensielt for å redusere risiko for kryssmitte mellom CF pasienter i og utenfor sykehus. Studien har avdekket generelt god kunnskap om tiltak for infeksjonskontroll, men også et behov for kontinuerlig samarbeid og opplæring for helsepersonell og pasienter i skriftlige anbefalinger for CF infeksjonskontroll.

Nyckelord
cystisk fibrose, infeksjonskontroll, hygiene, anbefalinger, interprofesjonellt team

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Nordic School of Public Health
NHV

MPH 2013:6
Dnr U12/06:362

Master of Public Health
– Thesis –

Examensarbetets titel och undertitel				
Awareness of Infection Control within Cystic Fibrosis Health Care – a Scandinavian study				
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Date of approval 13.12.2013			Supervisor NHV/External Marita Gilljam, MD/PhD	
No. of pages 67	Language – thesis English	Language – abstract English	ISSN-no 1104-5701	ISBN-no 978-91-86739-62-1

Aim: This study aimed to illuminate awareness of hygiene regimens and infection control guidelines for cystic fibrosis (CF) care at Scandinavian cystic fibrosis centers (SCFCs) and Norwegian cystic fibrosis satellite teams (NCFSTs).
Method: We modified a knowledge, attitudes and practices (KAP) survey used earlier for CF and infection control care teams in the United States. Our modified questionnaire sought responses regarding sputum cultures, hand hygiene, education and infection control measures in hospital/at home. We distributed individual questionnaires to 8 SCFCs and 10 NCFSTs. Awareness exceeding 75% per item was considered sufficient for clinical practice.
Results: Respondents represented different disciplines at SCFCs with 61 (37%) and 30 (58%) at NCFSTs core team professionals (mainly doctors, nurses and physiotherapists). SCFC respondents demonstrated higher KAP (range 49-100%) than NCFST (range 23-100%). Both groups showed a high awareness of outcome expectancy for selected guideline components (80-100%), but only moderate awareness regarding familiarity. Additionally, both SCFC and NCFST respondents demonstrated greater awareness of items connected closely to practical care and medical treatment (73% and 80% versus 93% and 74% respectively). As opposed, SCFC and NCFST respondents showed lower awareness of guideline content (49% and 23% respectively).

Conclusion: Because infection control is a cornerstone in CF care, reducing the risk of cross infection among CF patients in health- and non-health care settings requires health care professionals to maintain increased awareness of CF guidelines. This study revealed generally good knowledge of infection control measures. Importantly, best care requires continious collaboration and education for health care professionals and patients regarding the written guidelines for CF infection control.

Key words
cystic fibrosis, infection control, hygiene, guidelines, inter-professional team

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Abbreviations

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CF	Cystic fibrosis
CFTR	Cystic Fibrosis Transmembrane conductance Regulator
CFF	Cystic Fibrosis Foundation (USA)
ECFS	European Cystic Fibrosis Society
KAP	Knowledge, attitude, and practice
ACSM	Advocacy, communication and social mobilisation
SCFSC	Scandinavian Cystic Fibrosis Study Consortium
SOC	Sense of coherence (salutogenesis)
CDC/HICPAC	Centre for Disease Control and Prevention and Healthcare Infection Control Practices Advisory Committee
SCFC	Scandinavian Cystic Fibrosis Centres
NCFST	Norwegian Cystic Fibrosis Satellite Teams

Introduction

Cystic fibrosis (CF) is a genetic (autosomal recessive) progressive, complex and incurable multisystem disease with manifestations in the respiratory, gastrointestinal and fertility systems. Mutations in the CF gene cause defects in the glycoprotein Cystic Fibrosis Transmembrane conductance Regulator (CFTR); a glycoprotein of major importance for chloride and sodium transport across the cell membrane (1). A defect in the CFTR protein results into imbalance of the ion concentration both inside and outside the cells. The clinical consequences include a viscous mucus and changed milieu in the lung leading to chronic bacterial airway infection, progressive pulmonary damage and respiratory failure. The recurrent respiratory infections require lifelong monitoring and antibiotic treatment, guided by respiratory tract cultures and resistance testing. There is a need for a high standard of daily protective hygiene with focus on reduction of infection through droplet and contact infection routes (2) and the general vaccination programme should be followed. Other CF organ manifestations are related to the gastro-intestinal system with pancreatic enzyme replacement treatment, and the endocrine system with CF-related diabetes being a common complication.

There are large variations in symptoms and morbidity, and the prognostic life expectancy is shortened (1). Data from the USA present a dramatic change in life expectancy for persons with CF from median predicted age of death of 0,5 year in the 1940's, 16 years in the 1970's, 29 years in the 1990's to 37 years in 2008. CF was still considered as a childhood disease twenty years ago (3). Improved treatment and an increasing number of lung-transplantations have contributed to improvement of life expectancy. In Scandinavia, the number of adults with CF is increasing (4-6) and today the majority of the Scandinavian CF population are adults (personal communication).

In 2003, the Cystic Fibrosis Foundation (CFF) in the USA published a consensus document on Infection Control guidelines for CF (2). This document presented background data and evidence-based recommendations for practices, and intended to decrease the risk of transmission of respiratory pathogens among CF patients from contaminated respiratory therapy equipment or contaminated environment, and thereby reduce the burden of respiratory illness. The Infection Control recommendations, based on original and review publications together with international experts' view and experience, shifted CF Infection Control towards optimising practice and improving patient outcome by reducing the risk of cross-infection between patients with CF. Subsequent to the US document, the European CF Society (ECFS) in their publication from 2005 "Standards of care for patients with cystic fibrosis" made a proper statement for clear Infection Control policy at every CF centre mainly to prevent cross-infection between patients in hospital care, and with social restrictions outside hospital (7).

In the field of tuberculosis, work methods of conducting "knowledge, attitude and practice" (KAP) (8) surveys have been used for planning for control of tuberculosis – and "advocacy, communication and social mobilisation" (ACSM) strategy. The method has also been used in CF care in the follow-up study of the CFF Infection Control Guidelines 2003 for CF (9). The study assessed potential barriers to adherence to these guidelines experienced by health care professionals caring for CF patients. Most respondents were members of the multi-professional CF care team, and had many years of experience in CF healthcare. Suboptimal awareness of Infection Control guidelines was identified. The study demonstrated barriers to CF Infection Control as lack of knowledge, attitude issues and non-adherent practice within the multi-disciplinary team. Poor adherence to guidelines has been described as reflection of barriers experienced by health care professionals. The conclusion of the study was that there was a need for strategies to reduce barriers to adherence to CF Infection Control guidelines.

A follow-up survey (2008) (10) demonstrated that many CF care sites had local written Infection Control guidelines, reflecting the consensus guidelines. Some sites showed lack of written guidelines, and not all guidelines were consistent with the evidence-based recommendations. The results revealed that written guidelines might not correlate with true practice. A review publication (2009) focused on adherence to CF Infection Control guidelines from health care professionals. Strategies should include quality improvement initiatives with enhanced education and skills workshops, sharing successful interventions among CF centres - and linking adherence to improved patient outcomes (11).

A recent study from the Scandinavian Cystic Fibrosis Study Consortium (SCFSC) revealed differences between Scandinavian countries in the prevalence of chronic airway infection with *P. aeruginosa* infection (4). The authors discussed whether the result was due to different treatment intensity of intermittently colonised patients. Cross-infection between patients at the CF clinics was not a problem. Segregation policies have major implications for hospital care, social life, patient organisations and possibilities to arrange summer camps, meetings and other activities for CF-patients. New health care policies with increased restrictions will also affect the possibility of patient education within CF care, using the principle of patients learning from each other face-to-face or in groups.

A publication from the ECFS focusing on treatment and control of infections states that the chronic bacterial infection contributes to tissue damage and is the primary cause of long-term complications and death, and that the number of exacerbations per year is significantly correlated with patient age. The most common bacteria detected, causing chronic infections for patients with CF, are *P. aeruginosa*, *Staphylococcus aureus*, *Haemophilus influenzae* and the *Burkholderia cepacia complex* (7). There is an international agreement of protective hygienic standard and specific CF Infection Control, but there is also an international disagreement of the degree of the virulence of bacteria and restrictions as cohort-segregation (bacterial group) and individual protective isolation. The scientific evidence is still limited, and therefore difficult to interpret (12-15). Clinical practice is dependent of scientific evidence as well as expert opinions, resulting in differences of practice on a national, Scandinavian and international level – well known for patients with shared care (16-19).

A recent publication focuses on the challenge of an increasing numbers of individuals with CF becoming infected with the multidrug-resistant non-tuberculousis mycobacterium (NTM), *Mycobacterium abscessus*, which causes progressive lung damage and is extremely challenging to treat, and strict hygiene measurements are discussed. Route of acquiring this organism is not currently known, but there is growing concern that person-to-person transmission could occur. The study revealed frequent transmission of multidrug resistant *M. abscessus* between patients with cystic fibrosis, despite conventional cross-infection measures. The exact cross infection route is not established, but epidemiological analyses suggest indirect transmission (respiratory treatment and testing) (20).

In the widescreen window of international public health, there is a growing concern of the lack of new antibiotics in the drug pipeline, a reality dominated by reuse of old antibiotic products – now mainly as inhaled antibiotics in CF care. Also, emergence of antibiotic resistance, complicated infections, international differences in treatment of bacterial and virus infections, and a travelling population both domestic and abroad which increase the risk of acquiring infection. In summary, public health is influenced by a constant audit of evidence-based recommendations for Infection Control including microbial monitoring, basic hygiene regimen, patient logistics, vaccine prophylaxis and recommended antibiotic treatment in general and specialist health care.

CF is defined as a Rare Disease, which is based on the definition of a disease or disorder that affects less than 1 in 2000 citizens (international definition). Characterisation of rare diseases is by a broad diversity of disorders and symptoms that have variations not only from disease to disease, but also from patient to patient suffering from the same disease. Common problems for people with rare diseases are delay of diagnosis, lack of scientific knowledge of the disease, and inequities and difficulties in access to treatment and care throughout life (21-25). A Norwegian study (26) about experiences from being a patient with rare diagnosis admitted to the hospital, revealed that even if the doctors and other health care professionals lack necessary knowledge about the patients specific disorder, they extremely seldom consult with other specialist in order to acquire vital knowledge. The study also described failing routines of information between units in the same hospital, and between hospitals – also reported from shared care of CF patients.

Relevant previous research

During the last 20 years, evidence of cross-infection between patients, in and outside hospital settings, has caused a change in the view and practice of Infection Control for patients with cystic fibrosis (1,6,27-34). A recent review (19) discuss the virulence of CF pathogens including epidemic strains, complex understanding of droplet transmission and bacterial contamination of CF clinics as well as barriers to Infection Control guidelines. Findings from the study suggested that intervention with performing hand hygiene measures during clinical visits might reduce the risk of contamination in CF clinics. The conclusion stated that it is critical to understand the barriers to implementation of guidelines experienced by healthcare professionals and by CF patients and their families.

A Norwegian study from 2001 (27) indicated cross-infection with *P. aeruginosa* between CF patients. One large cluster, representing 45% of the patients included was identified. These cluster patients harboured the same bacterial strains and this was associated with participation at summer camps and different training courses. At these camps and courses no hygienic measures were taken to prevent cross-infections. The study could not identify an association with regular hospital admissions and shorter social events. As a consequence of this study, the Advisory Board of the Norwegian Cystic Fibrosis Association, introduced hygienic measures to patients, families and health care professionals to prevent cross-infection between patients with CF.

An Australian publication demonstrated evidence of cross-infection with a hospital clonal strain of *P. aeruginosa* at a paediatric CF clinic, affecting a number of young patients with serious cystic fibrosis lung disease and with fatal outcome for five children under the age of five (31). As a consequence, the hospital introduced preventive cross-infection measures with cohort segregation and educational seminars.

In a review (2,13) of Infection Control in Cystic Fibrosis the authors state that "Standard precautions, transmission-based precautions, appropriate hand hygiene for health care workers, patients and their families, and care of respiratory tract equipment to prevent the transmission of infectious agents serve as the foundation of Infection Control and will hopefully contribute to prevent the acquisition of potential pathogens by patients with CF".

A multi-centre study from the SCFSC (4) revealed that segregation of patients at the outpatient clinic according to *P. aeruginosa* colonisation status was not practiced in any Swedish centre, in contrast to Danish and Norwegian centres.

- Bacteriological cultures from non-sputum-producing patients were obtained less often in Sweden compared to Denmark and Norway, where laryngeal aspiration was performed at every visit. The policies for segregation of patients infected with *P.*

aeruginosa differed with strict segregation at the centres in Denmark and Norway, but not in Sweden.
- Differences were huge in practical CF care and medication, including use of antibiotics. Results indicate lack of common Scandinavian treatment recommendations. Already at start of the study there was an awareness of many of the differences.
- The prevalence of *P. aeruginosa* chronic infection was low in all Scandinavian centres when compared to other published data.

Risk for patient-to-patient transmission is associated with contamination from CF respiratory pathogens at inpatient settings. A study of bacterial contamination in cystic fibrosis clinics (34) showed that contamination of respiratory pathogens from CF patients' hands and the clinic environment occurred, but the actual risk of patient-to-patient transmission in the outpatient setting was difficult to quantify. The findings support several CF Infection Control recommendations, including hand hygiene for health care professionals and patients, contact precautions for certain pathogens, and disinfection on surfaces in the clinic. It is a well-known challenge for workplaces and professionals to make use of the knowledge already existing in the organisation, described as the experience-based knowledge or organisational know-how. Together with user-based knowledge and research-based knowledge they form evidence-based knowledge highlighted for organisational innovation and improvement.

Learning in health organisations is described in a Norwegian textbook (35,36) as how to exploit, and make use of research-based knowledge about the learning process. The most valuable learning in an organisation takes place through daily practice, in social relations between colleagues, and within the culture, norm and values represented at the working place. Learning is connected to relation and has a sense of affiliation and common goals. The development of knowledge will be anchored in the situation, and within colleagues working together. Workplaces has to develop a culture based on employees learning from each other, and find this natural to practice and experience together when they solve their work tasks.

New methods for treatment of infections have contributed to a better survival for patients with CF, but not always to sanitising of pathogens and infections (7).
An impaired defence in lungs and airways, recurrent lung infections with various microbes and a progressive reduction in lung function throughout life characterise the CF respiratory disease. Prolonged lifespan and frequent antibiotic treatment will likely increase the risk of emerging antibiotic resistance. Infection Control as protection and prevention of cross-infection – at home and in health care institutions, and other social environments are of great importance (3). Keeping a high standard of hygiene regimen will convey major positive and negative consequences for the CF-patients, CF-population, social opportunities, health care and health economy.

The European Cystic Fibrosis Society performed a follow-up survey to health care professionals in the European CF centres and units regarding implementation of standards of care-control and treatment of infection (7). European CF Consensus Guidelines are widely adhered to, and Infection Control policies were implemented by most respondents (77%). One area of improvement was to separate infected patients. The responding CF centres of the study represent 80% of the approximately 30.000 patients with CF in Eastern and Western Europe. An expert review publication (30) summarises that a number of studies have demonstrated that people with CF can disseminate bacteria into the air, and this may represent a potential route for cross-infection. But, the route of cross-infection is still unknown. It could be not one single route of cross-infection in health care settings, but also a combination of airborne routes via droplets or droplet nuclei, and by direct contact and indirect contact via contaminated equipment and health care workers.

Nordic and public health perspective

The Nordic Ministerial Council has since the 1970's supported the Scandinavian CF network between Denmark, Sweden and Norway. The other Nordic countries, where CF is a very rare disease, have not participated. Activities included annual meetings for the three national patient associations and health care professionals from CF centres and hospitals for information and discussion of health care strategies, with the aim to improve CF care. In the Scandinavian countries there are now >1400 persons cystic fibrosis, and the life expectancy is increasing, while the approximate number in the Nordic countries Finland is 50 and Iceland 10.

The SCFSC Study from 2009 (4) included 989 patients (48% female) from the eight CF-centres in Denmark (359 patients), Sweden (428 patients) and Norway (201 patients) (2). This represented 86% of the Scandinavian CF-population. Approximately 60% of the patients were more than 18 years. Registered lifespan was 0-70 years. The best result of health and survival in CF is reached by systematic and close lifelong follow-up by a specialised multidisciplinary CF team (1). Shared care is challenging for collaboration, coordination and competence, and in several studies shared care is a risk for disease progression and poor prognosis for patients with CF (4). Different health models in the Scandinavian countries may affect treatment and follow up at different levels of health care (one-, two- and/or three levels of shared care) for the patients. The geographic differences between the countries affects the health model chosen.

In 1981, Denmark changed the CF infection control policy and chose cohort isolation for patients infected with *P. aeruginosa,* as a consequence of emerging epidemic spread of bacterial strains (37). The result was a reduction of intermittent infection from 34% to 17% and a reduction of new cases from 16% to 9%. This has been revised several times for pathogens and resistance patterns, and other pathogens have been added to the cohort regimen. These recommendations are applied to all activities organized by the CF patient association. During the years 1981-1995, the introduction of cohort isolation and early intensive inhalation treatment with antibiotics, following the initial isolation of *P. aeruginosa,* resulted in a reduced incidence and prevalence of chronic *P. aeruginosa* infection (38). For treatment of chronic infection with *P. aeruginosa* repeated, elective intravenous antibiotic courses for 14 days was introduced.

After revealing evidence of cross-infection between Norwegian CF-patients (20), the Advisory Board for the Norwegian Association for CF revised the guidelines to focus on improved individual infection control at home, in non-hospital and in hospital settings; with recommended use of single rooms for CF patients in hospital, individual physiotherapy treatment, personal inhalation equipment also for use in hospital, no bubble bath and improved hand- and cough hygiene.

Following completion of the SCFSC study 2009, an epidemic resistant *P. aeruginosa* strain was detected in Sweden despite rigorous hygiene precautions (28,29). Strict Infection Control routines were required for these patients and the new situation was discussed among CF centres and with the patient's organisation. Since no patients were infected at the clinic, most precautions and changes in routines were regarding patient organisation activities. At Oslo University Hospital (Norway), during a period in 2006, several children were diagnosed with *P. aeruginosa*. All patients had visited the in- and out-patient care the preceding year. Cross-infection was suspected and extensive surveillance, including cultures and genotyping of all *P. aeruginosa* strains, demonstrated that all patients had individual strains (non-published data). This confirmed that no cross-infection between these CF patients had occurred. In 2010, the same situation aroused with possible cross-infection among some of our young patients, but the same microbiological procedure concluded that no cross-infection had occurred.

The guidelines from the National Public Health Institute in Norway, regarding basic Infection Control for health care (39), apply to interaction with all patients independent of suspected or unsuspected diagnose or assumed status of infection. This is a protection against infection for health care professionals, and prevention of cross-infection between patients. The National Institute for Health Data and Disease Control (Statens serum institutt) in Denmark has basic recommendations for hygiene, which are incorporated in all clinical recommendations for prevention of infection between patient and professionals, professionals and patient, and patients and patient (40). The Swedish Institute for Communicable Disease Control (Smittskyddinstitutet) has recommendations of basic hygiene routines as the most important preventive measure for avoidance of infections in health and social care. The guidelines include hand wash and hand disinfection, use of gloves when needed and protection gown when in close contact with patients (41).

A Norwegian study on people with rare disorders (respondents included patients with CF) and their experiences with public health and welfare services documented barriers that can be related to the fact that the disorder are labelled "rare". Professionals involved tended to base their judgement on their professional assumptions, consequently followed by incorrect actions (42). A Swedish publication describes the consequences of increased differentiation of roles, tasks and responsibilities in health care. Patients, especially those with diversity of needs, may get lost as a result of fragmented delivery of care. Integrated care pathways and strategies for dissolving this "Patient Bermuda Triangle" of specialisation, centralisation and professionalisation are discussed (43).

A Scandinavian CF care policy with collaboration has developed during the last decade, with annual meetings for the different health care professions. As a result of discussions of differences in managed CF care and managed CF care; a growing number of Scandinavian research projects have been performed. At the annual Scandinavian CF care collaboration meetings, CF health care policies are discussed. Scandinavian studies have revealed differences in between the countries and centres and it is a challenge to interpret the results and which implications the results will have for the local CF centre. In autumn 2011 the CF Associations in Denmark, Sweden and Norway directed an inquiry to the Nordic Ministerial Council for an "openness of care strategies and patient outcome results between the Scandinavian CF Centres" (44), by implementation of targeted quality improvement of the Scandinavian CF health care, and equality of health care services for CF patients. In Denmark, the CF Centres together with health authorities and national CF Association have decided to publish this information on web sites.

Relevant theoretical framework

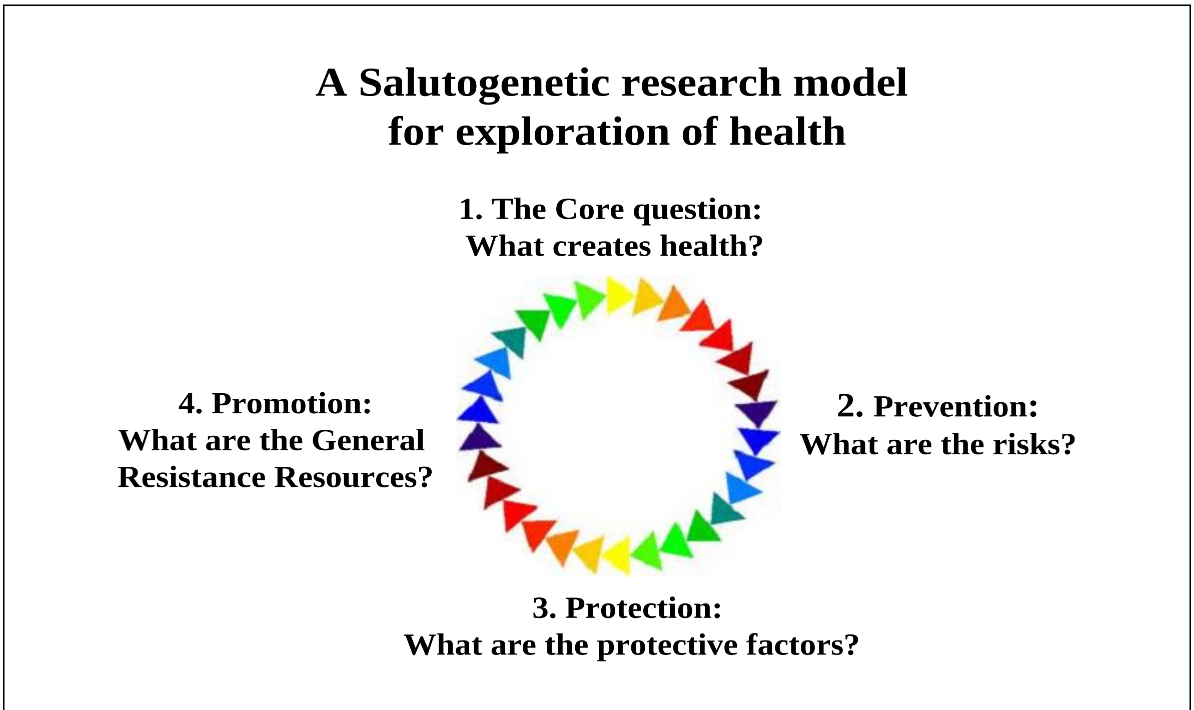
Salutogenesis

What creates health? Aaron Antonovsky, the American-Israeli medical sociologist, introduced the salutogenic framework with the idea of the importance to focus on people's resources and capacity to create health rather than the classic focus on risks, poor health and disease.

"Salutogenesis", the origin of health, is a stress resource oriented concept, which focuses on resources, maintenance and improvements of the movement towards health. It gives the answer why people despite stressful situations and hardships, stay well. The theory can be applied at an individual, group, and a community level. It is the opposite of the pathogenic concept where the focus is on obstacles and deficits. The ability to comprehend the whole situation and the capacity to use the resources available was called the Sense of Coherence (SOC). This capacity was a combination of peoples' ability to assess and understand the situation they were in, to find a meaning to move in a health promoted direction, also having the capacity to do so – that is, comprehensibility, meaningfulness and the manageability.

The original definition of salutogenesis by Antonovsky is "a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that: 1) The stimuli from one's internal and external environments in the course of living are structured, predictable, and explicable; 2) The resources are available to one to meet the demands posed by these stimuli; and 3) These demands are challenges, worthy of investment and engagement."

Antonovsky also stated distinctly, that salutogenesis was not limited by the disciplinary borders of one profession, but rather an interdisciplinary approach and a question of bringing coherence between disciplines, and realising what connects them. Furthermore, it is not only a question of the person but an interaction between people and the structures of society – that is, the human resources and the condition of living context. The salutogenic research model for exploration of health is as a circle with four stages starting with 1) the core question, 2) the prevention, 3) the protection and 4) the promotion (fig 1) (45-47).



Adapted fig. from ”The Hitchhikers' Guide to Salutogenesis”
Bengt Lindstrøm & Monica Eriksson, 2010

Figure 1: A Salutogenic research model – with comprehensibility, manageability and meaningfulness of life.

Quality improvement – evidence-based health care

Evidence-based practice is characterised by making decisions based on research and experience-based knowledge and patients' wishes and needs in the given situation. By identifying important questions among users of healthcare services and healthcare professionals the need for research-based knowledge is visualised. Different methods of systematically obtained knowledge and use of relevant publications will contribute to that informed decisions are made. For health care, the clinical applicability is of real interest.

The circle of Plan-Do-Study-Act (Deming Circle) is often used is as a method for quality improvement – a systematic method for problem solving. Centre for Evidence Based Health Care in Norway recommends this method to improve health care practice and patient outcome (48,49). The process for quality improvement has six dimensions (quality star) influencing the change of health care services towards: 1) Be effective, 2) Be protective for people, 3) Be available and fairly distributed, 4) nvolve and empower users, 5) Have coordination and continuity, and 6) Safety and security.

Health Care as learning organisations

The concept ”learning organisations” was introduced as a vision describing a group of people who are continually enhancing their capacities to create what they want to create (50). The five basic disciplines to be collective for innovation are system thinking, personal mastery, mental models, building shared vision, and team learning with mastering the practices of dialogue and discussion. These disciplines can be approached at one of the three levels – practices (what you do), principles (guiding ideas and insights), and essences (the state of being those with high level of mastery in the discipline).

As there are different ways of working together, a lot of terms expressing interprofessional work (51,52) are used. There is a disagreement within the academic community of definitions and content, and the professions tend to relate the terminology and theory with their own discipline to this issue. The process of balancing the different professions opinions, which makes a basis in dynamic collaboration, is related to integration of competence and service from the professionals. This is an area for potential solutions, but also conflicts. Discussion exist within the interprofessional team discussions, requiring reflections and negotiations, but there will also be necessary conflicts and struggle for power (53).

Development and new science within organisational work will influence on professionals' collaboration and working strategies in health care, especially when innovation for improvement is needed. Professionals' willingness and interest for change may be a barrier, and adaptation to evidence-based health care may prove to be difficult. During recent years an increasing attention has focused on how interprofessional teams can improve professional relationships, collaboration and quality of care. It is often assumed that the way professional relations should be managed and care delivered, is by teamwork in practice (51).

Communities of practice are a unique combination of three elements: An area of knowledge, which defines a collection of topics, the community of people who cares for these topics, and a common practice they have developed together. Just because the participants have a shared an area of knowledge and a common interest, they are inspired to help and participate. This participation will also function as a guide for teaching and give meaning to actions.

A functioning community will promote interaction and relations based on mutual respect and trust, and a willingness to share ideas. A community of practice requires an atmosphere of transparency where it is safe to tell the truth, and safe to ask a difficult question where trust is the key to this processes – as about dissolving the Patient Bermuda Triangle (43). Yet, a community of practice is not without conflicts. But the stronger the community, the better for dealing with disagreement, and the members may use conflicts to strengthen both relations and learning. To summarise, learning in organisations can be perceived as a structure of knowledge, and a question of knowing (know-how and know-what) in actions, where actions are integrated processes determining characteristics of learning processes (35,36).
Recently, an altered view of conflicts has been discussed, from destructivity for collaboration to be constructive as prerequisite for progress and innovation. Disagreement and differences can promote positive effects by discussing, and expanding new insight of issues. The importance of disagreement could benefit interprofessional work by working through inequality, and come forward with the differences in view of issues. By dealing with conflicts more constructively within interprofessional work, they may act as opportunities for development and creativity – a learning process (54).

Conceptual framework

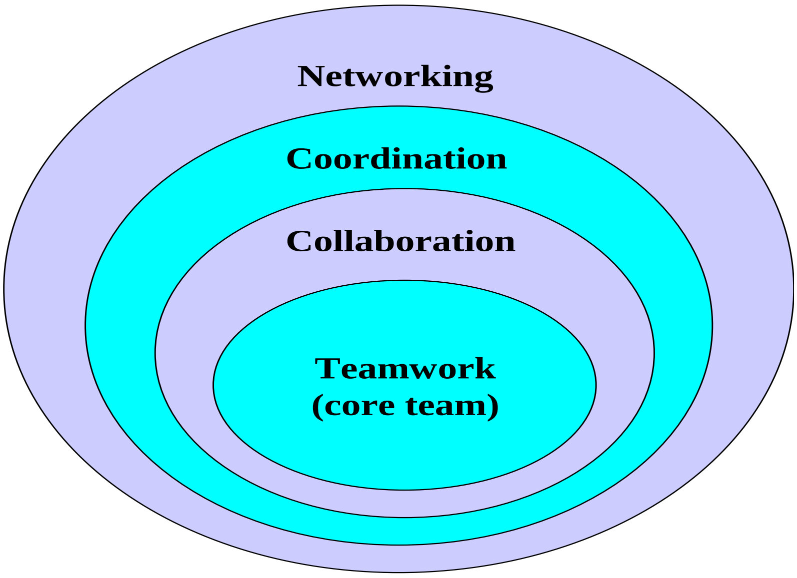
Health Promotion work is defined as the process that make people capable of improving and preserving their health and is described in the Ottawa Charter, WHO 1986 at the first International Conference on Health Promotion (55). Health is seen as a resource for everyday life, and not the objective of living.

The model and theory of salutogenesis as systematic exploring of health towards the health end of the health – unhealthy continuum, is connected to health promotion (45-47).

The World Health Organisation (WHO) describe infection control as "infection prevention and control measures aim to ensure the protection of those who might be vulnerable to acquiring an infection both in the general community and while receiving care due to health problems, in a range of settings. The basic principle of infection prevention and control is hygiene" (56,57).

In health care today there are different forms of interprofessional work, and team-form development has followed a change where the prefix "inter" characterize a greater degree of interaction and integration compared to "multi" equivalent to multi-professional work between organisations and services. Multi-professional work describes profession groups working beside each other, or parallel, with strongly separated subject field, and where there may be a hierarchical relation between the profession groups. Interprofessional work describe several professions working closely together on a common project or common task, and where greater degree of interaction and integration of ideas and activities between collaborating partners. Different forms of interprofessional work are teamwork (core team), collaboration, coordination and networking (fig 2).

Interprofessional work can be viewed as an activity founded on different key dimensions as: Evident goals (primary goal for effective patient/client care), share team-identity, share obligation, evident team roles and responsibility, dependence between team-members and integrated work practice. Interprofessional collaboration challenges with variations of professions, competence, team and different types of collaboration for optimising patient care (51).



Differing forms of interprofessional work
Adaptet from Reeves at al 2010:
Interprofessional Teamwork for Health and Social Care

Figure 2: Differing forms of interprofessional work from teamwork to networking

Infection Control for cystic fibrosis care is focused on reducing the risk of cross-infection by droplet, contact or air transmission of secretion from respiratory tract (lungs and airways) between patients with CF.

At the individual level this is

1. Monitoring microbial and symptom status, antibiotic treatment after microbiological and antibiotic sensitivity testing, infection prevention with recommended vaccination and standard precaution measures including individual mucus mobilisation respiratory treatment,
2. Protective isolation in hospital, single room or isolation room with controlled air flow ventilation, social isolation from other patients with CF if infected with certain virulent pathogens (not attending meetings or courses together with other

persons with CF), compliance of standard and individual hygiene in everyday life, daily cleaning and disinfection of treatment equipment together with aseptic handling of medications and equipment.

At the system level this is

1. Monitoring microbial and symptom status within the CF population at clinic, antibiotic treatment after culture and sensitivity testing, and recommended vaccines.
2. Optimising standard and specified hygiene regimen, providing single or isolation room in hospital, social isolation of patients with infected with certain virulent pathogens, providing individual mucus mobilisation respiratory treatment, daily cleaning and disinfection (and autoclaving with specified pathogen) of respiratory treatment equipment (in Norway recommendation to use private nebuliser in hospital).
3. Patient administration and patient pathogen logistics for acute and planned short and long-term hospital stay with planned and co-ordinated patient care pathway in hospital, and non-hospital integrated health care included respiratory treatment with the local physiotherapist.
4. Regularly meetings (annual or more often if needed) between the different professionals and health care specialities involved in CF care either at the same hospital, or the different hospitals in shared care.

The revised CFF evidence based recommendations for Infection Control in cystic fibrosis care are based on the principles that "CF pathogens are transmitted by the droplet and contact routes" (2,12,13). Health care practice must implement preventive measures to reduce the risk for transmission of respiratory tract pathogens between patients, and this must be followed with all CF patients independent of the specific microbiological results of individual CF patients. Culture specimen will not always be representative of the respiratory tract flora and microbiological methods are not 100% sensitive for the detection of CF pathogens. Respiratory tract cultures should be obtained at least quarterly in CF patients with stable pulmonary status as well as at the time of pulmonary exacerbations. Recommendations for room placement, activities outside the hospital room, CF clinic logistics, and adjuvant measures to prevent infections are provided. Disinfection and sterilisation are basic principles for the specific use and care of respiratory therapy equipment recommended to all patients with CF. Standardised protocols for cleaning to remove organic debris and disinfecting respiratory therapy equipment are important in healthcare settings where equipment is used by more than by one patient, as well as findings from investigations of outbreaks of infections associated with contaminated respiratory equipment (6,12,13).

Regularly meetings between the CF team and collaborating specialities, as microbiologist, will optimise patient monitoring and treatment. Measures for the standard hygiene included hand hygiene, contact and droplet prevention have been developed by Centre for Disease Control and Prevention and Healthcare Infection Control Practices Advisory Committee (CDC/HICPAC) to prevent healthcare-associated infections in all patients, both CF and non-CF patients (58). The consensus document of European Standards of CF Care (1) defines Standards for routine evaluation, monitoring and treatment for best outcome for European CF patients – and this includes Infection Control policy similar to CFF Recommendations. Close collaboration with regular meetings between microbiology and all CF specialists are needed for best care, and the same is valid for different types of shared care.

Aim and research question

The aim of the study was to illuminate awareness of hygiene regimens and Infection Control in practice by health care professionals within Cystic Fibrosis Health Care in Denmark, Sweden and Norway.

Research question

How is the awareness to CF Infection Control guidelines within the interprofessional team at the Scandinavian CF Centres and the Norwegian CF Satellite Teams?

Method

The survey is based on a self-administered, semi-quantitative questionnaire with a combination of multiple-choice questions and open questions. Preferred language for the questionnaire was English, rather than translated to Danish, Swedish and Norwegian. All questions was discussed, and perceived easy to understand. Maintaining original language was considered best since comparison of the studies was part of the aim originally, but later excluded. Respondents could choose to answer in English or native language. Adjustment of survey and construction of additional questions was performed by investigator and supervisor with focus on spelling, readability and completion time. No pilot survey was made. Number of questionnaires distributed was based on the number of staff persons, as estimated by the contact person at each centre or satellite team. It was also added a small number of questionnaires to health care professionals working with CF patients at the hospital wards (not employees at SCFC or part of NCFST) for every SCFC and NCFST.

The study was performed as a survey of hygiene regimen and Infection Control with individual questionnaires to two different groups of participants:

- Part 1 – the Scandinavian CF Centres in Oslo, Bergen, Gothenburg, Lund, Uppsala, Stockholm, Aarhus and Copenhagen. This was as a “follow-up” study from the SCFSC 2008 (2).
- Part 2 – the Norwegian CF Satellite teams in Tromsø, Bodø, Levanger, Trondheim, Ålesund, Stavanger, Arendal, Tønsberg, Elverum and Oslo.

The Norwegian Resource centre for Cystic fibrosis is located at Oslo University Hospital, and is a part of the Department for Rare Diseases. The CF Satellite team is part of the ordinary clinical patient care at the same hospital for this health region in Norway.

Practical planning of the study

The study was conducted from winter 2010 to early autumn 2011 (last return in spring 2012).

Part 1: The questionnaires were distributed during early spring 2011 with requested return within four weeks. Reminders were given by email after three weeks. Main contact at the centres was the centre leader (doctor), and communication form was email. Nurses, informed at the Scandinavian Nurse Specialist Group meeting, were responsible for the distribution and return of the questionnaires.

Part 2: The questionnaires were distributed spring and early autumn 2011. Reminders were given by email after three-four weeks. Main contact at the satellite hospitals was the senior doctor, and communication form was email. Nurses were responsible for the distribution and return of the questionnaires. They had been informed at the Cystic Fibrosis Forum for Nurses in Norway.

Study design and survey

After reading the publication “Barriers to Infection Control guidelines” (12) initiative by e-mail was taken to the Cystic Fibrosis Foundation in US for contact address with the researcher in charge, Lisa Saiman, MD, Prof., (17.01.2010). After a short e-mail dialogue with Dr Lisa Saiman, a copy of the KAP Survey for Cystic Fibrosis and Infection Control Care Teams in the United States was received together with permission to use in this study (16.02.2010). A document from WHO and StopTB-Partnership describes a KAP survey (knowledge, attitude and practice) survey as a representative study of a specific population to collect information on what is known, believed and done in relation to a particular topic. The survey can identify gaps, cultural beliefs, or behavioural patterns that may facilitate understanding and action, as well as pose problems or create barriers for control efforts as infection prevention and control (8). KAP surveys may be used to identify needs, problems and barriers in programme delivery, as well as solutions for improving quality and accessibility of services.

Original semi-quantitative multiple-choice survey was analysed and discussed for use in the Scandinavian CF Centres, and a decision was made for adapting the questionnaire with some minor changes and supplementary questions:

- Comments (filling in) at eight questions (11-14, 21-24)
- New questions (33-34, 41-44)
- Question 33-34 in original survey was removed
- Total number of 45 questions, included five questions with six sub-analyses

The original CFF survey is designed to explore potential barriers to adherence for KAP to five selected components of Infection Control guidelines:

1. Obtaining quarterly cultures from the respiratory tract of patients with CF,
2. Discouraging socialisation among CF patients during hospitalisation,
3. Educating patients and families about hand hygiene,
4. Educating patients and families to clean and disinfect home nebulisers, and
5. Cleaning the clinic exam rooms between patients.

Table 1: Definitions of Sufficient Awareness for Knowledge, Attitude and Practice to Infection Control Guidelines in Cystic Fibrosis used in survey

Awareness to Infection Control Guidelines in Cystic Fibrosis *Sufficient Awareness defined as >75% of time/opportunities* *Lack of awareness defined as <20% awareness*	
Knowledge	• Sufficient awareness – knowledge of Infection Control guidelines • Sufficient awareness of familiarity – familiar with guidelines in general or with specific guidelines
Attitude	• Sufficient awareness of agreement – agreement with specific guidelines • Sufficient awareness of self-efficacy – perceived awareness of confidence or awareness of preparation of respondents to perform specific guideline(s) • Sufficient awareness of outcome expectancy – awareness of belief by respondents that guideline(s) will lead to an important health outcome
Practice	• Sufficient awareness of frequency (adherence) – how often guideline(s) performed • Sufficient awareness of external factors – awareness of factors that could impact performance of guideline(s): awareness of time during clinic visits, support staff, administrative support, financial reimbursement, and/or educational materials for patients
Modified from original table from "Barriers to adherence to Infection Control guidelines" (Garber et al 2008)	

For this study the survey was extended with open fields for comments on some questions, and in addition five questions concerning:

- Change of Infection Control recommendation, attitude or practice after the SCFSC study (4)
- Local Infection Control guidelines
- Comments on additional issues related to Infection Control in CF

The original survey is described as a modification of previously described KAP surveys, with use of:

- Three-point (e.g. not familiar, somewhat familiar, or very familiar) or
- Five-point response scale (e.g. strongly disagree, disagree, neutral, agree and strongly agree).
- Respondent's characteristics (e.g., profession), and external factors (e.g. lack of time or support staff) were assessed.
- Questions about awareness of the guidelines and familiarity with specific guidelines were placed at the end of the survey so that the respondents completed the survey regardless of awareness of the guidelines (9).

For better harmonisation with the theoretical framework of salutogenesis and quality improvement in health care it was decided to change focus from lack of awareness to sufficient awareness of CF Infection Control guidelines.

Study sites and participants

Informants were selected from the multi-professional team at:

Part 1 – Scandinavian CF centres in Oslo, Bergen, Gothenburg, Lund, Uppsala, Stockholm, Aarhus and Copenhagen.
All centres participated in the SCFSC study (4). One of the participating centres (Oslo) has almost exclusively full time employees, while for the majority of the CF centres there are only a few full time positions for CF, mainly nurses, doctors, physiotherapists and secretaries. The number of part time employees varies between 20-80 %, and at some centres there are additional staff working with projects. All CF Centres have close collaboration with in-hospital units.

The staff at the hospital wards seldom has specific knowledge of CF and the CF centre will keep the main responsibility for the admitted patient. Information from the SCFC describes affiliations of approximately 52 health care professionals working full time and around 91 working part time in total. Invitation for participation was open to all employees at the CF centres. Local Infection Control team members were not primarily invited to participate in the study, mainly because the CF team take responsibility for monitoring and implementation of Infection Control care for their CF patients.

In the second part of the study, and in analogy with the Survey of Infection Control Policies for patients with Cystic Fibrosis in the United States, informants from the collaborating hospital wards in Norway were invited to participate in the study:

Part 2 – Norwegian CF Satellite Teams in Tromsø, Bodø, Levanger, Trondheim, Ålesund, Stavanger, Arendal, Tønsberg, Elverum and Oslo.
These units are the same that participated in the Norwegian data collection (at local hospitals) for the SCFSC study (4), with all collected data managed by the study coordinator at the CF Centre in Oslo.

All of the NCFST are part of shared patient care in collaboration with the national CF Centre in Oslo. All employees at the NCFST were invited to participate in the study. Local Infection Control team members were not primarily invited to participate in the study, but the CF team was given the opportunity to include collaborating health care professionals at their hospital.

Data collection

Individual questionnaires were distributed and returned by ordinary mail. All responses were informed to be confidential. No staff identifiers would be collected. A unique study number identified the sites, and only aggregated data would be analysed and reported.

Part 1 – Scandinavian CF Centres
An e-mail with invitation for participation in the study was sent directly to centre leaders. The study was also presented at the SCFSC meeting. Acceptance was answered by e-mail from centre leaders. Questionnaires were mailed by ordinary post to the CF Centres. Distribution to individual professionals at the CF multi-professional team was organised from the centre directly, mainly by centre leader, medical doctor or nurse.

Part 2 – Norwegian CF Satellite team
An invitation for participation in the study was sent by e-mail directly to the senior doctor and the nurse. Acceptance was answered by email. Questionnaires were mailed to the teams that accepted to participate in the study. Distribution to team members was organised by the contact person, usually the medical doctor or nurse.

Data analyses
Data analyses following definitions from the original survey by Garber (9):

- Adherence defined as a respondent considered to have acceptable adherence if a guideline was practiced > 75% of the time/opportunities.
- An item considered a barrier to adherence if >20% of subjects responded negatively.

To identify potential barriers to adherence was assessed by dichotomising the 3- or 5-point scale following the original survey definitions of barriers:

- Lack of familiarity by responses “not familiar” and “somewhat familiar”
- Lack of agreement by responses “strongly disagree”, “disagree” and “neutral”
- Lack of self-efficacy by responses “not confident”, “somewhat confident” and “moderately confident”
- Lack of outcome expectancy by responses “no effect” and “minimal effect”
- Lack of awareness by responses “no” and “not sure”, “not familiar” and “somewhat familiar”,

External factors on ability following guidelines was considered as:

- Risk by responses “slightly significant”, “moderately significant”, “very significant” and “extremely significant”.

Table 2: Beneficial Impact of Awareness to CF Infection Control Guidelines on Adherence, Familiarity, and Attitude Barriers used in survey

Beneficial Impact of Awareness to CF Infection Control Guidelines on Adherence, Familiarity, and Attitude Barriers – survey items	
Adherence to guideline	Educate CF patients to clean and disinfect home nebuliser after use
Familiarity with guideline	Overall content of guideline* CF patients should avoid socialisation during hospitalisation Educate CF patients to perform hand hygiene Educate CF patients to clean and disinfect home nebuliser Clean exam rooms between CF patient use
Agreement with guideline	Quarterly cultures of respiratory tract are useful for CF CF patients should avoid socialisation during hospitalisation
Self-efficacy (confidence in ability to practice guideline)	Collect quarterly cultures of respiratory tract Educate CF patients to clean and disinfect home nebuliser Discourage socialisation between CF patients during hospitalisation
Outcome expectancy (belief that practicing guideline will improve patient outcome)	Discourage socialisation between CF patients during hospitalisation Clean and disinfect home nebuliser

*Modified from original table from “Barriers to Adherence to Cystic Fibrosis Infection Control Guidelines” (Garber et al 2008) * International, national and local guidelines*

Following the original survey for impact of access to guidelines on adherence (with example educating >75% of patients to perform hand hygiene) and barriers to adherence (by responses disagreement with specific guideline) was assessed. The results are mainly presented as numeric and categorical data, and part of the different answers in the extraneous categories will be compared. Formulations of the questions make a graphic statement possible. Excel 2000 was used for data sorting, analysing and graph presentations. The focus of this study was on awareness rather than barriers. Respondents accentuate all positive results for illustrating possible change and improvement of KAP. This was a similar process as described in the recent publication by Saiman (19) with improvement of infection control adherence.

Ethical permission and consideration

Some dilemmas with this survey were addressed and discussed, such as the challenge of Scandinavian health care colleagues to participate for a comparison of awareness of CF hygiene regimen and patient outcome. Survey language could be a barrier, although most CF publications are written in English. A translation of the questionnaire to three different Scandinavian languages was regarded as a risk for unexpected changes of questions, and making comparison difficult. Another ethical challenge could be that the non-respondents turned out to be professionals with less experience, or professionals not working regularly with CF care, and respondents turned out to be professionals with best awareness of CF Infection Control, and used to English written publications.

In the interests of person anonymity it was decided not to compare the collected data centre-to-centre and team-to-team. The Scandinavian CF Centres represent small communities with multi-professional teams, and one single person represents some professions. The Norwegian CF Satellite Teams are even smaller communities, and with greater difficulties in keeping anonymity of obtained information. All returned questionnaires are confidential information. No staff identifiers were collected. Instead a unique study number, available to the investigator, identified the sites. Only aggregated data were analysed and reported.

An application was sent the Regional Ethical Committee (REC) in Norway in order to consider if agreement from the participating countries was needed for this Scandinavian survey. The reply was that no formal approve was necessary as this was formally a project for quality improvement in health care. The study was approved by the Head of the Paediatric Neurological Department and the Research leader at the Department of Paediatrics at Oslo University Hospital – Ulleval Hospital. Request for use of IT-server for Qualitative Research was granted.

Results

There were 37% (61 (62)/166) questionnaires accepted for the SCFC part of the study and 58% (30/52) for the NCFST part. One SCFC respondent was excluded as site identification number was removed before return. A majority of the respondents from SCFC were health care professionals working most of their time in CF care; in comparison to the respondents from the NCFST working very little of their hospital time in CF care. Of the total study respondents there were 5% nutritionists, 4% psychologists and no social workers. Reasons to decline participation were perception of weakness of anonymity of the questionnaire, unwillingness due to limited knowledge about recommended infection control for cystic fibrosis, and language barriers to answer a questionnaire in English.

Reminders increased response rate from SCFC with 10% and NCFST with 50%. A total of three reminders were sent to the SCFC, and the last response was received in September 2011. A total of three reminders were sent to the NCFST, and last response was received in May 2012.

The analyses performed in this study are similar to, and following descriptions from the study by Garber (9). The possibility for statistical analysis was limited, and statistical comparison with the original study was not performed. Not all respondents answered all questions in the questionnaire, some with the explanations of not relevant, or no explanation listed.

Question 1-5 was regarding respondents and site characteristics. Median respondents at question 6-43 were 52 (of 61) for Scandinavian CF Centres and 29 (of 30) for Norwegian CF Satellite Teams.

Survey part 1 – Scandinavian CF Centres characteristics

All eight SCFC were invited and participated in the study with two centres in Denmark, four centres in Sweden and two centres in Norway. A total of 166 questionnaires were distributed with 61 (37%) accepted. The CF centres had the possibility to include all employees, and also other health care professionals at in- and out-units from their own hospital. Calculation of error margin showed that there is a 95% certainty to assume that if all questionnaires had been returned, answers would be within +/- 10,0% of all answers in this study part (59).

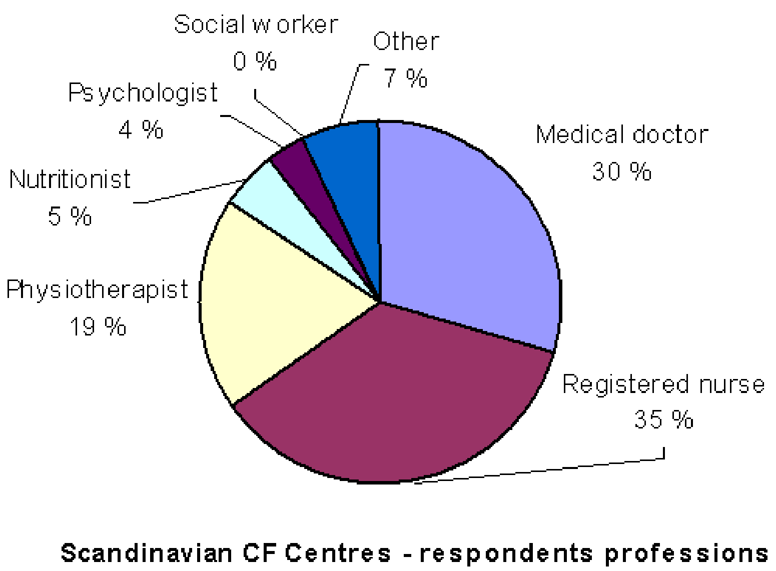


Figure 3: Scandinavian CF Centres – respondents profession

The participating SCFC were represented by medical doctors (all eight centres), nurses (seven centres), physiotherapist (six centres), nutritionist (three centres), psychologist (one centre), and others (two centres with technical assistant). No social worker participated. There was one CF centre with six of seven professions responding, one centre with five of six, four centres with three (professions,) and two centres with two professions responding.

The responding CF centres have a multi-professional team with doctor, nurse, physiotherapist, nutritionist (dietician), psychologist, social worker and secretaries. Two centres have technical assistant, one centre a bio-analytic, and one of the centres also a bio-medical technician. All CF Centres have a close collaboration with the hospital wards for pediatric and adult patients.

Table 3: Characteristics of the eight Scandinavian CF Centres

Scandinavian CF Centres – sites & characteristics

Sites	*Questionnaires distributed*	*Questionnaires returned*	*Years of experience (median)*	*Patient population**	*Centre type*
1	30	9 (30%)	<1-17 (8)	> 150	Local, regional, outreach**
2	20	4 (20%)	3->30 (12)	100 – 150	Local, regional, outreach
3	20	9 (45%)	<1-55 (9)	100 – 150	Local, regional, outreach
4	20	9 (45%)	1-32 (17)	100 – 150	Local, regional, outreach
5	30	13 (43%)	1-36 (13)	> 150	Local, regional, outreach
6	20	3 (15%)	5-30 (10)	100 – 150	Local, regional, outreach
7	8	5 (62%)	1-20 (10)	< 50	Local, regional, outreach
8	18	9 (50%) 1 excl (5%)	2-30 (11)	> 150	National, local, regional, outreach
Total	166	61 (37%)	<1-55 (10,5)	≈ 1000	National, local, regional, outreach

**Patient population based on publication from Knudsen et al (2009) and personal comunication **Outreach describe activities or services outside hospital*

The vast majority of the respondents (99%) were members of a multi-professional specialist team, while 9% were members of hospital teams for in- and out-patient CF clinic. Total working time spent with CF-related activities was “most of the time” for 61% (range 75-100%), “up to half of the time” for 27%, and “more than half of the time” for 2% of the respondents. The highest participation in the study was by the core team members at each centre (fig 3).

Distribution of patient care was paediatric care 35%, adult care 33%, transplant care 31% and newborn screening 1%. All participating centres provided care for paediatric and adult patients, and also provided shared care, together with the transplant teams, after solid organ transplantation. Respondents for transplant care in the study are from the SCFC and NCFST. The specialist transplant team was not invited to the study.

Establishing CF newborn screening have been planned during the last years in Scandinavia, and is since spring 2012 included in an extended national newborn screening programme in Norway, that is after closing of this survey.

Survey part 2 – Norwegian CF Satellite Teams characteristics

Ten NCFST were invited and participated in the study. A total of 52 questionnaires were distributed with 30 (58%) in return. The local contact person proposed the number of questionnaires. Calculation of error margin showed that there is a 95% certainty to assume that if all questionnaires had been returned, answers would be within +/- 11,6% of all answers in this study part (59).

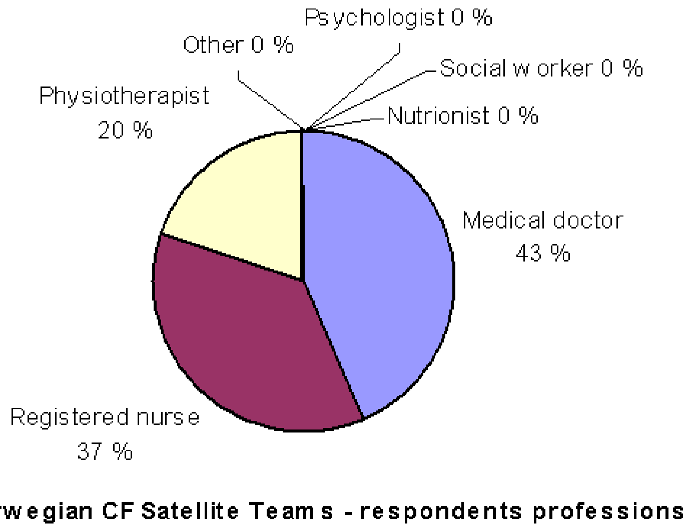


Figure 4: Norwegian CF Satellite Teams – respondents profession

The NCFST were represented by medical doctors (nine of ten centres), nurses (eight of ten centres) and physiotherapist (five of ten centres). Five NCFST had three of seven professions from questionnaire list responding, two teams had two professions and three teams with one profession responding. Distribution of patient care represented by the participating professions at the NCFST were paediatric care 42%, adult care 42%, and transplant care 16%. The patient care was divided between seven paediatric teams and eight adult teams.

Norwegian health care is decentralised both for specialist and community care. For patients with CF this represents a shared care on two or three levels applicable to all health care professions involved at local, regional and national care. Few hospitals in Norway have established CF teams as defined by the European Standard of CF Care.

Table 4: Characteristics of ten Norwegian CF Satellite Teams

Norwegian CF Satellite Teams – sites & characteristics

Sites	*Questionnaires distributed*	*Questionnaires returned*	*Years of experience (median)*	*Patient population**	*Centre type*
1	10	5 (50%)	10-20 (10)	> 150	Local, regional, outreach**
2	4	3 (75%)	9-13 (10)	> 10	Local, regional
3	3	2 (66%)	10-11 (10,5)	> 20	Local, regional
4	7	4 (57%)	6-24 (12,5)	> 20	Local
5	6	5 (83%)	1-15 (11,5)	> 40	Local, outreach
6	6	1 (16%)	15 (15)	> 10	Local, outreach
7	6	3 (50%)	10-20 (15)	>20	Local
8	4	4 (100%)	10-36 (13)	> 10	Local
9	2	1 (50%)	4 (4)	> 10	Local
10	4	2 (50%)	4-20 (12)	> 10	Local
Total	52	30 (58%)	1-36 (11,75)	< 200	Local, regional, outreach

**Patient population based on patient registry at the Norwegian Recourse Centre for CF*
***Outreach describe activities or services outside hospital*

At the local and regional hospitals CF patients are mainly cared for by physicians, nurses and physiotherapists with special interest in CF. Other professions collaborate when needed. Number of patient varies from > 5 to >20 patients (pediatric and adult in total) at each hospital. The team affiliations of 13% belonged to the interprofessional specialist team, while 87% were members of the hospital care team at in-patient and/or out patient clinic.

Total working time for respondents spent to CF-related activities was very little time (< 10%) for 89% and up to half of their time (10-50%) for 10% of the respondents. Only physicians, nurses and physiotherapists responded.

Awareness to Knowledge, Attitude and Practice from respondents

Sufficient awareness was defined as practicing a guideline >75% of the time or opportunities, and definition for lack of awareness was < 20% awareness.

Awareness to selected National and International CF infection Control Guidelines

This study demonstrated sufficient awareness for all five guideline components for outcome expectancy, and for almost all guideline components for awareness of agreement for both SCFC and NCFST. Awareness for familiarity and self-efficacy was below sufficient awareness for the NCFST respondents (table 5).

SCFC respondents demonstrated sufficient awareness for 14/19 (74%) of the questions, and this covered all five guideline components and most of the four different awareness categories. High score was seen for awareness of outcome expectancy with 5/5 for all guideline components, while the lowest score was awareness of familiarity with 3/5 components. Awareness of outcome expectancy for education of patients and families to practice hand hygiene had the highest achieved sufficient awareness. Lowest score for awareness of familiarity with the hospital hygiene measures between CF patients, and the monitoring of CF patients respiratory tract infections (table 5).

"It is very important that guidelines are based on evidence. Cross-infection is bad, but too serious guidelines according to infection control, has a major impact on the lives of our patients!"

SCFC respondents demonstrated sufficient awareness for education of patients and families with 4/4 categories for hygiene measurements for home nebulisers, together with 3/3 awareness categories for practicing hand hygiene. Comments were that they did not know the routines for cleaning and disinfecting home nebulisers, but that others in the team had this responsibility and patients are being informed that the major route of transmission is direct contact, and how to practice proper hand- and cough hygiene. Also comment of uncertainty of the effect of following the recommendations for hand hygiene and disinfection of home nebulisers on improving patient outcome.

"Appropriate hand hygiene goes together with coughing in the elbow, keeping one meters distance."

The Scandinavian policy to obtain quarterly cultures showed sufficient awareness from SCFC respondents for three awareness categories. Awareness of familiarity was lower, and could imply differences in detailed knowledge of practice from respondents. There were comments on the importance of individual treatment of children and severely ill patients, and for implementing early eradication treatment for difficult pathogens.

"Some patients who are only little affected by the illness don't need every 4-6 weeks. But children and severely ill patients have extremely large effect of cultures every 4-6 weeks."

SCFC respondents showed sufficient awareness according to the policy to discourage socialisation among hospitalised CF patients for self-efficacy and outcome expectancy, and the recommendations to clean clinic exam rooms between CF patients for outcome expectancy and agreement. Both items received high awareness for outcome expectancy indicating good knowledge of the issues, while the lower awareness of familiarity imply less detailed knowledge of hygiene measures in practice. Some commented that the need for discouraging socialisation and cleaning exam room depends on the pathogen. Others of the difference between cleaning only in special occasions, compared to cleaning in case of risk, and only when needed.

"Depending of bacteria."

From NCFST respondents sufficient awareness was demonstrated for 8/19 (42%) of questions for the five guideline components and the four different awareness categories. Highest score to awareness of agreement and outcome expectancy was seen for the hospital practice with obtaining quarterly cultures for monitoring respiratory infection status, and education for CF patients and families in practice of Infection Control measures. Awareness of familiarity and self-efficacy for all five guidelines components was below sufficient awareness, and this could indicate differences of knowledge, practice and responsibilities between expert team and the satellite teams.

"We are working on a more structural system for obtaining samples every 6 weeks. This due to lack of administration staff."

Respondents from NCFST showed the highest achieved sufficient awareness of outcome expectancy and agreement for obtaining quarterly cultures as the recommended Scandinavian policy, and to outcome expectancy for educating CF patients and families to practice hand hygiene.

"Quarterly as every 12 weeks is too seldom. Every 4 week is OK."

NCFST respondents showed sufficient awareness of agreement and outcome expectancy with education for patients and families to clean and disinfect home nebulizers, and for the hospital recommendation of clean clinic exam room between CF patients. Results indicate good knowledge of the issues.

"Not sure of rated effect on following recommendation for improving patient outcome based on my experience."

Results from NCFST respondents showed sufficient awareness for outcome expectancy for discouraging socialisation among hospitalised CF patients, and results implying less knowledge and adapted hygiene interventions according to the issue. Comments on that there were very seldom more than one patient hospitalised at the same time, and that the effect of preventive measures has been seen.

"Very seldom more than one patient hospitalised at the same time."

Table 5: Awareness of selected Cystic Fibrosis Infection Control Guidelines demonstrated with guidelines components and familiarity, agreement, self-efficacy and outcome expectance.

Awareness to selected National and International Cystic Fibrosis Infection Control Guidelines

Experienced by Health Care Professionals at Scandinavian CF Centres & Norwegian CF Satellite Team

Guideline component	*% Awareness of familiarity*	*% Awareness of agreement*	*% Awareness of self-efficacy*	*% Awareness of outcome expectancy*
Obtain quarterly cultures (Scandinavian policy every 4-6 weeks)	68	**84**	**83**	**96**
	70	**100**	70	**97**
Discourage socialisation among hospitalized CF patients	71	75	**77**	**80**
	47	62	44	**80**
Educate CF patients and families to practice hand hygiene	**78**	Not asked	**82**	**100**
	54	Not asked	63	**100**
Educate CF patients and families to clean and disinfect home nebuliser	**84**	**88**	**85**	**98**
	50	**90**	64	**97**
Clean clinic exam room between CF patients	57	**85**	60	**80**
	40	**83**	49	**80**

Scandinavian CF Centres – white / Norwegian CF Satellite Teams – shaded
Sufficient awareness > 75% of subject/time/opportunities / Lack of awareness < 20% awareness
Table adapted after Garber et al (2008)

Knowledge awareness

SCFC showed 49% awareness to the overall contents of CF guidelines. When split into three different guidelines the results revealed that the awareness of CFF Infection control recommendation (6) 62%, for ECFS Standards of care (1) 66%, and for SCFSC (4) were 60% respectively. Comments from SCFC respondents about familiarity of the three guidelines were based on information from their colleagues, participating at CF conferences, reading CF publications, CF information at Internet and annual nurses meeting. Several respondents participated in the SCFSC study (4). The SCFC showed 73% awareness to survey components as "potentially transmissible pathogens in respiratory tract secretions from all CF patients", and for "securing a single patient room for CF patients with multidrug-resistant organisms" an awareness of 93%.

"From my colleagues and former centre director."

NCFST showed 23% awareness to overall contents of CF guidelines, and results for the three different guidelines revealed awareness of 36% for CFF infection control recommendation (6), 41% for ECFS Standards of care (1), and 27% for the SCFSC study (4). Familiarity from NCFST respondents was based on information from their colleagues, communication with CF centre in Oslo, participating at annual national meetings, CF course and CF nurses seminar. The NCFST showed 80% awareness to survey components as "potentially transmissible pathogens in respiratory tract secretions from all CF patients", and for "securing a single patient room for CF patients with multidrug-resistant organisms" an awareness of 74%.

"At CF Meeting in Oslo, CF Centre."

All of the SCFC reported access to local Infection Control guidelines, both for CF with pathogen-specific guidelines and general hospital guidelines. National CF guidelines for *P. aeruginosa* in Sweden and national CF Infection Control guidelines 1998 from the Advisory Board of the Norwegian CF Association. Comments from SCFC respondents had referral to importance of Infection Control guidelines based on evidence for CF, according to the negative impact for patients with isolation and discouraging socialisation both inside and outside of hospital. Also referral to individual physiotherapy for patients, and stricter Infection Control recommendations for patients with special pathogens.

"Yes, some of the Infection Control guidelines follow general hospital precautions outlined in local guidelines."

NCFST respondents have learned about the CF Infection Control recommendations at CF Conference in Copenhagen, CF Association in Norway, national CF meting, and from colleagues. Not all respondents have read the original publications. Comments of local/national CF Infection Control Guidelines from NCFST respondents referred to local electronic handbook for patients at the hospital, and from the Norwegian CF Centre. Recommendation for Infection Control from the advisory Board at The Norwegian CF Association and Ulleval hospital does not cover all aspects of this issue.

"At CF Nurses annual meeting."

Attitude awareness

Respondents from SCFC showed an awareness of agreement with 75-88% for all guideline components, with lowest rate for discouraging socialisation between hospitalised CF patients (table 5). Comments of discouraging is dependent on type of pathogen. Awareness of self-efficacy was 60-85% from SCFC respondents, with lowest rate for cleaning clinic exam room between CF patients (table 5). Respondents from SCFC stated that type of cleaning procedure is depending on type of pathogen, applied to exam room and respiratory test equipment.

"Depending on bacteria."

Respondents from NCFST showed an awareness of agreement with 62-100% for all guidelines components (table 5). Lowest result was for discouraging socialization among hospitalised CF patients. Some comments referred to seldom more than one patient hospitalised. From NCFST respondents the awareness for self-efficacy was 44-77% for all survey components, with the lowest rate with 44% for the ability to prevent socialisation between hospitalized CF patients (table 5). Respondents from the NCFST commented of "no actuality of cleaning exam room between CF patients, because of only one patient".

"Use different rooms."

Factors for practice & ability to follow

External factor for practice affecting the ability to follow selected CF Infection Control items demonstrated moderate to low awareness for most survey components (table 6).

SCFC respondents showed lowest rate for cleaning exam room between CF patients with 41% for sufficient support staff. Moderate awareness for survey components was demonstrated with 60-75% with sufficient educational material for patients, together with 62% for education time for health care professionals.

"We only clean the lung function machine, and after patient with risk behaviour (no hand hygiene)"

NCFST respondents showed low rate for cleaning exam room between CF patients with 33% awareness for sufficient support staff. Also low rate for survey components as 32% awareness of sufficient in-service training, 37% for sufficient support staff, and 38% education time for health care professionals for the ability to educate CF patients and their families to clean and disinfect home nebulisers equipment.

"Other professions educate patients to practice proper hand hygiene."

Estimation of factors for practice from SCFC demonstrated moderate awareness. The lowest rates was 22% for personal instruction from respondent of cleaning and disinfecting home nebulisers, and 38% for percentage of CF patients at their centre having respiratory tract cultures every 4-6 weeks. Best score for discouraging CF patients from socialising during hospitalisations.

"I see my patients between every 4-12 weeks depending on severity of their disease – they are always cultured at the clinic visit – provided they have been off antibiotics at least three days prior to clinic visit."
"MRSA, B.cepacia complex, Multiresistant gram negative, P.aeruginosa, other gram negatives" (discourage socialisation.)
"Probably the nurses. We do not have a routine for this" (hand hygiene.)
"Nurse and physiotherapist" (home nebulizers).
"Depends of bacteria type" (cleaning room between patients).

Table 6: Ability to follow selected Cystic Fibrosis Infection Control items in clinical practice demonstrated with survey components

Ability to follow selected Cystic Fibrosis Infection Control items
Experienced by Health Care Professionals at Scandinavian CF Centres & Norwegian CF Satellite Team

Survey component – % sufficient time/opportunities	*Time during visits*	*Support staff*	*Administrative support*	*Financial re-imbursement*	*Educational material for patients*	*Time to educate*	*Space*	*In-service training*	*Time for education (internal)*
Collect cultures of the respiratory tract from CF patients at centre every 4-6 weeks.	**78**	74	**78**	**80**	75	-	-	-	-
	71	69	75	**82**	71	-	-	-	-
Discourage CF patients from socialising together during hospitalisation.	-	**76**	**76**	-	60	74	58	-	-
	-	59	**79**	-	75	68	48	-	-
Educate CF patients and their families to practice proper hand hygiene while waiting in the clinic.	-	66	**80**	-	60	60	-	65	-
	-	50	69	-	52	50	-	44	-
Educate CF patients and their families to clean and disinfect their home nebuliser equipment.	-	69	**78**	-	66	-	-	**76**	62
	-	37	69	-	42	-	-	32	38
Ensure that the exam rooms are cleaned between CF patients.	43	41	66	-	62	-	-	66	-
	52	33	67	-	59	-	-	50	-

Scandinavian CF Centres – white / Norwegian CF Satellite Teams – shaded
Sufficient ability > 75% of time/opportunities / Lack of ability < 20% ability

From NCFST estimation of factors for practice demonstrated mostly moderate awareness. The lowest score represented lack of awareness for personal instruction for cleaning and disinfecting home nebulisers, and close followed with 21% for personal instruction of practice proper hand hygiene. Best score for cleaned exam rooms between CF patients.

"They are adult patients. We strongly recommend testing every 6th week, but some of them don't want to do it either" (respiratory tract cultures).
"MRSA, B. Cepacia, Pandorea apista" (discourage socialisation).
"Childrens Unit here and Norwegian Centre for CF" (hand hygiene).
"CF centre / CF specialists" (home nebulisers).
"Only one patient" (cleaning room between patients).

Awareness of change

Awareness of change of recommended CF Infection Control guidelines after the SCFSC study (4) was 33% from SCFC, change of attitude 21%, and change of practice 25% respectively. Comments from the majority of the SCFC respondents were that no changes had been made, but one centre had new hospital recommendations from 2008. However, in Sweden the activities organized by the patient organisation have been stricter, specifically regarding camp activities, and one centre reported improvement in obtaining regular cultures. Patients free from *P.aeruginosa* and other opporunistic bacteria can attend camps but with certain regulations.

"We have not changed, except we have become better to obtain regular cultures."

From NCFST respondents reported 3% awareness of change for all three survey components with recommendations, attitude and practice for CF Infection Control.

"Our attitude and practice have been changed, and I am of course familiar with these changes."

Beneficial Impact of Awareness to CF Infection Control Guidelines

Beneficial impact of awareness to CF Infection Control was sufficient for 10/13 guidelines components for the SCFC, while three guideline components showed moderate awareness of familiarity. Lowest awareness was demonstrated for familiarity of the overall content of CF guideline. Results indicate that SCFC respondents have a more specific discipline knowledge connected to profession and practice in CF care, which have influence on the awareness for CF Infection Control guidelines. Personal experience also depended on the practical consequences in hospital care, and size and complexity of microbiology pathogens within the CF patient population. Teamwork and collaboration, supervision and exchange of experience contribute to awareness for CF Infection Control. Regular team meetings and annual meetings contribute to improvement in CF care.

Beneficial impact of awareness to CF Infection Control was sufficient for 3/10 components for the NCFST, while nine guideline components showed moderate awareness. Close to lack of awareness was demonstrated with familiarity of the overall content of CF guideline. Results indicate that NCFST respondents seem to have more detailed knowledge in connection to the few CF patients in their hospital care, and that special CF care consequences have acceptable practical solutions in the hospital care. Close collaboration with the CF centre for supervision of individual treatment, and annual meetings contribute for improving CF shared care.

Best results for both study parts with nearly identical results was demonstrated for “discouraging socialisation between CF patients during hospitalisation”, “quarterly cultures of respiratory tract are useful for CF”, and “clean and disinfect home nebuliser”. Sufficient awareness is defined as >75% of opportunities, and the results demonstrate a space for improvement of guideline components (table 2) for both SCFC and NCFST respondents when illuminated with beneficial impact of awareness on KAP (fig 4).

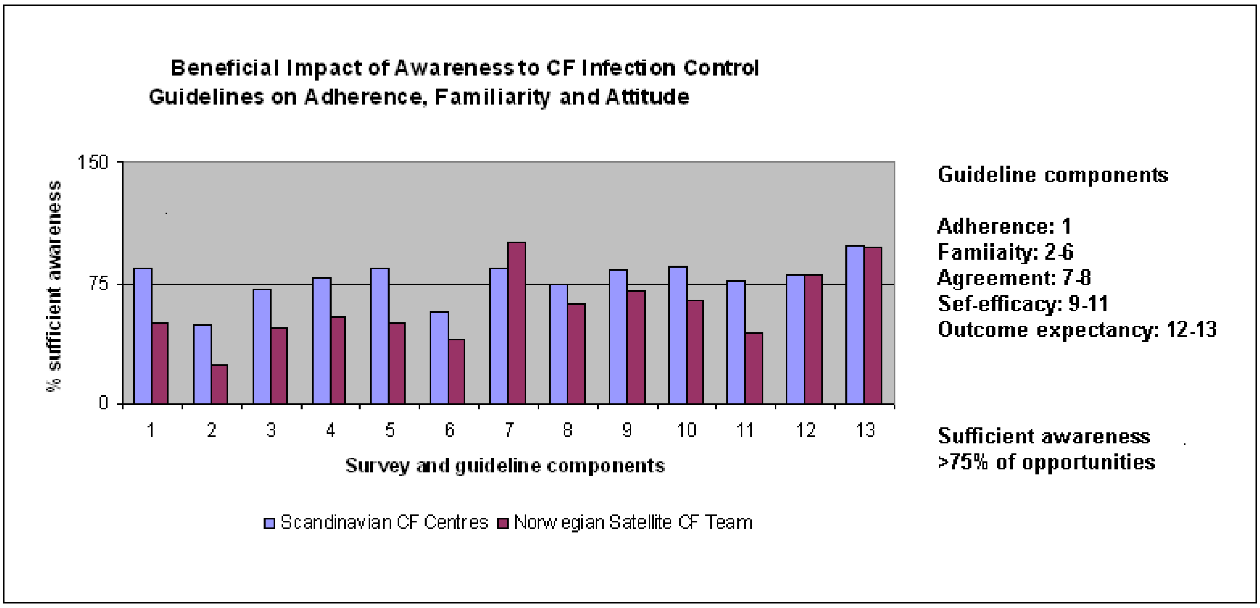


Figure 4: Beneficial Impact of Awareness to CF Infection Control Guidelines On Adherence, Familiarity and Attitude

Discussion

To our knowledge, this is the first Scandinavian study on professional awareness of Hygiene Regimen and Infection Control Recommendations for Cystic Fibrosis. In Norway the Advisory Board for the Norwegian CF Association made a study on *P. aeruginosa* strains in Norwegian CF Patients (27), and studies on bacterial strains have been conducted in Sweden and Denmark as well (28,29,37,38).

Challenges with surveys & questionnaires

Different challenges have been described with use of surveys; in association with study population, questionnaire language, formulation of questions, testing, number of respondents, analysing process, study period, type of distribution and collaborating persons. We recognised some of these challenges; for example how to distribute the questionnaires for a good response rate. For motivation and to increase the number of respondents information was sent by e-mail, and repeated as written in invitation letter. The study investigator was also available by e-mail and phone. Study period included common holidays and work permission for employees at both study parts, and may also be an explanation for the low participation.

Barriers recognised for not participating in this study was English language in the questionnaire, lack of knowledge / not competent to answer, and possible lack of anonymity for respondents. This is mainly information from contact persons. Based on information from study sites it is likely that non-responders represent employees not working on a regular basis with CF. It is a possibility that returned questionnaires represents respondents with best awareness of CF Infection Control guidelines and familiarity with English-written publications.

Median number of respondents for question 6 – 43 was 52 (of 61) for SCFC and 29 (of 30) for NCFST. Question 1-5 was respondent characteristics.

Focus of the analyses of this study was to describe and interpret similarities and differences between the two study parts, and also to compare the result with Garber (9). No statistical analyses were made because of the descriptive nature of the study and for the cause of anonymity of respondents.

This study has provided information about practices and perceptions for respondents of several professions from SCFC and NCFST concerning Infection Control for CF patients within hospital care.

Hygiene Regimen and Infection Control in Scandinavian CF Care

Experience of CF Infection Control is closely connected to clinical practice for health care professionals. The various measurements are based on microbial findings from patients' respiratory tract cultures, situations of risk for transmission, and recommended hygiene regimen to reduce cross infection. Depended on type of profession, and involvement in clinical care with CF patients, the individual experience will differ. This will likely affect the differences and similarities of knowledge and attitude within and between the professionals at the CF Centres. Similar findings are demonstrated in this present study for both study parts.

Respondents from the SCFC represent different health care professions with variable work experience and knowledge of CF Infection Control. Within an multi-professional team the responsibility and tasks are divided depending of professions, and this may influence to less detailed knowledge in specific issues (table 6). SCFC respondents had a variability of detailed knowledge and nearness to practice for the CF population in their hospital care. As anticipated, the SCFC respondents demonstrated a high level of awareness for KAP in CF infection control for most guidelines and survey components (table 5). The respondents from the NCFST's represented with less diverse professions with variable length of work experience and knowledge of CF Infection Control, mainly doctors and nurses together with few physiotherapists. NCFST showed detailed knowledge and nearness to practice for the very few CF patients in their hospital care.

The NCFST respondents demonstrated a moderate to high level of awareness for KAP in CF Infection Control for most guidelines and survey components (table 5), but also less detailed knowledge in specific issues (table 6). In both study parts the main respondents were doctors and nurses, closely followed by physiotherapists, the three professions in the CF team responsible for Infection Control measures in the clinic and on the hospital ward. An important and positive finding was the high KAP result for the important guideline components of the study for both study parts (table 5). The awareness for the "overall contents of the CF Infection Control guidelines" was low with a joint average of 36%, demonstrated with 49 % from the SCFC respondents, and only 23% from the NCFST, respectively. That makes a contrast to the very high level of awareness demonstrated for detailed guidelines as "potentially transmissible pathogens with all CF patients" with average joint sufficient awareness of 76,5%, and "securing a single room for patients with multidrug-resistant organisms" with average joint sufficient awareness of 83,5%.

The SCFC respondents had an average awareness of 72% for the three survey components, while the awareness of respondents from the NCFST showed an average awareness of 59%. The results of the present study indicate respondents' reservation regarding detailed and specific knowledge of the written CF Infection Control guidelines while the knowledge of some key features of the CF care, including basic hygiene regimen, single rooms for CF patients and protective measures to prevent patient-to-patient transmission, seems to be sufficient. Items with close connection to practical care and medical treatment seems to have a higher awareness from respondents from both parts of the study. This kind of knowledge is useful in the daily health care for best possible Infection Control for CF patients in hospital, and can be transferred directly to individual patient care.

Infection Control is also a tool for patient logistic in hospital, both in basic and CF health care on an individual and a system level. This systematic logistic strategy for CF hospital care seems to be more in use at the SCFC compared to the NCFST, justified in the view of reducing risk for cross-infection in hospital between patients. The need for systematic Infection Control monitoring increases with growth of patient population, however always needed for the individual patient care and best disease outcome – as in general hospital care and in specific CF hospital care. Even if the familiarity with the guidelines was above 75% for only 2/5 items for SCFC and 0/5 for NCFST (table 5), the belief that awareness to the guidelines will improve outcome for CF patients was high for all items. The most important is to know what to do and why, and not to be able to cite the guidelines. The discrepancy can be explained by the fact that some guidelines are incorporated in the organisation of the clinic and thus followed also by professionals with no or minor knowledge of the written content.

The survey components “clean clinic exam room between CF patients” was demonstrated differently with lower awareness for familiarity and self-efficacy for both SCFC (57 and 60%) and NCFST respondents (40 and 49%) (table 5). Discouraging socialization among hospitalised CF patients showed lower awareness for NCFST (47 and 44%), and was probably less of an issue with very few patients to care for. SCFC responders commented that they had learned about CF Infection Control guidelines mainly from participating in national and international CF meetings, and from colleagues. They also referred to international publications and websites. For the NCFST the regional/local guidelines, national meetings and collaboration with CF Centre in Oslo were recorded as important sources for information. Fewer NCFST respondents had read the original publications. The SCFC showed a high level for awareness of most of the guideline components of selected guidelines, while the NCFST was very close at some. The results indicate knowledge of CF disease and treatment recommendations, and the contribution to CF patients’ health from Infection Control measurements at hospital both at central, regional and local level with adapted information.

Infection Control for best CF patient logistics

Patient logistic in hospital is based on preventive Infection Control including continuous microbial monitoring, with CF patients scheduled individually with time space between the patients, and good waiting areas in the clinic, or directly transferred to a patient room at the clinic (2,12). By this Infection Control regimen, strict segregation is not an issue. Most important, patient education in CF hygiene recommendations for use in hospital and at home, and respectful behaviour and awareness with hand- and cough hygiene will reduce risk of patient-to-patient transmission of pathogens.

The extent of introduction and implementation of CF Infection Control guidelines in Denmark, Sweden and Norway is not known, but as a result of the SCFSC (4) differences in hygiene regimen and antibiotic treatment between these countries and CF centres was documented. Policy for antibiotic inhalation regimen differ between the centres and higher total antibiotic load and more days on inhaled antibiotics may suppress bacterial growth and explain differences in percentage in patients with chronic *P. aeruginosa* infection. Another explanation could be the difference in segregation policy at in- and out-patient settings, with different wards for different pathogens. At some centres few patients are admitted to hospital because of the standard regimen of home treatment with intravenous antibiotic.

“Obtaining quarterly cultures” showed slightly less awareness for familiarity, but Scandinavian policy is every 4-6 weeks (4). Norwegian policy is to perform laryngeal suction for non-expectorating patients at all ages, and this policy has also been introduced at CF Centres in Denmark and Sweden. In Denmark, sterile mouth swabs have been used for respiratory tract cultures, well known from international CF practice. Some Swedish centres perform bronchoscopy with broncho-alveolar lavage for bacterial cultures on clinical indication in non-expectorating children. Respiratory tract culture is the diagnostic tool to identify type of pathogens causing lung infection, and monitoring resistance pattern for best choice of antibiotic treatment, and as a logistic preventive infection control practical measurement of CF patient care in hospital. For Infection Control and when cross-infection is suspected, genotyping methods for determination of bacteria strains are required – as recently documented from CF Centres in UK; a cross-infection with *M. abscessus* (20).

Estimation of factors for practice was low for both parts of respondents, and almost lack of awareness (19-22%) for "instructing patients on cleaning and disinfecting of home nebulisers." A similar result was recorded for the NCFST respondents for instruction on hand hygiene (21% awareness). Lack of definition is defined as < 20% ability. Comments gave information that only nurses and physiotherapists were responsible for hygiene instruction for patients' home nebulisers at the CF centres, explaining the low number. Teaching patients proper hand hygiene was CF centres nurses' responsibility in general. These results demonstrate that tasks as hygiene regimen are divided between the professionals, either between core team members at centre or satellite hospital (at the same level of health care), or between the centre team and the satellite team (at different levels of heath care).

A good communication between health care professionals is important for securing effectiveness also regarding patient education, which should be considered as part of health care practice, and included in the annual assessment. Education should follow adapted checklists, and given information recorded in the patients' medical files (19). External factors influencing the ability to follow selected CF Infection Control Items showed sufficient administrative support for most survey components for both parts of respondents, while a lower ability for "cleaning exam rooms between CF patients" and "support staff" was demonstrated. These findings can be connected to low awareness for estimation of percentage of exam rooms cleaned between CF patients in clinic. Respondents have commented that the type of pathogen decide cleaning process, and some use different exam rooms.

Modern Infection Control for hospitals recommends single room for all patients used both at in- and out patient clinic, and with health professionals moving from single room to single room for the individual patient care (6,12). Special hospital room for treatment, testing and investigation (medical treatment, physiotherapy, respiratory testing, radiology,) require operative routines also for basic Infection Control logistic included microbiological information, effective hospital visits and reduced time at waiting areas, practical patient care, cleaning and disinfection (19). With increasing size of the patient population the risk for cross-infection will increase and consequently also the need for specific CF hygiene regimen.

Improving CF Health Care

In Scandinavia the disease Cystic Fibrosis is regarded as a Rare Disease (22-25). Most health care education programmes have information about CF, but often only as part of genetic science. Few health care students have experience from CF care during study practice, with the consequence of low knowledge and competence of CF in health care services. Experience from doctors and patients with rare diseases in Norway support this, and indicate results with a non-sufficient and lack of collaborative health care for patients with chronic diseases and rare disorders (26). In most countries, CF is part of centralised specialist health care responsibilities. In Denmark and Sweden this specialist health care is organised as recommended CF centre care with some shared care, in contrast to Norway with a decentralised specialist health care also for patients with CF, and a national resource centre with restriction on clinical care included in the mandate. The model with shared care requires close collaboration between the involved professionals, and with the experts at CF centres in the lead as described in international CF guidelines. Shared care may be a risk for disease management and patient outcome (1).

Publications from USA about improving CF Centre Care illuminate factors of success demonstrated during collaborative projects with evidence-based practice as: 1)Well-functioning care teams that work to ensure that they provide consistent care; 2) High expectations for outcome among providers and families; 3) Early and aggressive management, with little reliance on rescues – the teams seek to reverse small declines or complications before they become obvious; 4) Patients/families that are engaged, empowered and proactive, and well informed on disease management and its rationale. This partnership with teaching the essentials of quality improvement, and the promising results with great progress in CF patient outcome demonstrated in the following annual reports from CF registries (3, 49, 60-62). Now, CF Centres in Europe adapt to this collaboration and use the results from CF registries to improve CF care (7). In Scandinavia, both Sweden and Denmark have national CF registries, and report to the European CF Registry, but not Norway.

Education and in-service training of CF Infection Control was less sufficient for both study parts, with lowest awareness for NCFST. This finding indicates a need for improvement of health professionals understanding of the specific CF Infection Control, compared to basic Infection Control. Close collaboration between CF Centre and local/regional health care is needed for patients with shared care. Similar collaboration is also needed when patients are transferred to other clinics and settings, as from paediatric to adult care. Unfortunately, publications have documented poor effect on education regarding changed behaviour, such as Infection Control recommendations for hand hygiene (9,11,19).

The SCFC and the NCFST respondents reported low awareness (33% and 3%) for any changed CF Infection Control recommendations after the SCFSC study (4). However, in general the awareness of Infection Control measures and the belief in their importance was much higher than the awareness of the exact content or changes of the written guidelines. In Norway, Infection Control recommendations were revised in 1998 after cross infection between Norwegian CF patients had occurred (8). When the fact of cross infection between patients is proved, a change of Infection Control recommendation for practice is required. Comments from respondents confirm awareness of minor changes in recommendation and practice, which can be considered as local quality improvement.

Several studies have shown that information of new science and access to treatment recommendations in health care differ substantially among health care professionals, as for CF care (9). Also, among patients and families there is documented lack of knowledge, understanding and compliance of the new guidelines for Infection Control in CF care (10). Knowledge is closely connected to phenomenon as tradition, resources and measures, and to change dissemination of knowledge can mean breaking barriers for a final change implemented in practice (3,35,36,49). This study show a possible benefit from education and inter-professional collaboration within CF Infection Control, regarding the low awareness of the three CF Infection Control guidelines and recommendations referred to in the study. Comments from respondents revealed that inter-professional collaboration and local/national meetings are good opportunities for teaching and information. But, these findings enhance the need for improvement of guideline components elucidated in this study, and this is a necessity for further improving patient care and outcome for cystic fibrosis.

Lack of awareness can change to risk situations and risk behaviour from health professionals, patients and relatives, which can cause cross infection between CF patients and re-infection for individual CF patient. What to learn, and how to improve?

A European publication (60) points out that the quality improvement of CF care can be assessed by evaluation of practices and outcomes between CF centres using summaries of electronic patient records and patient registries. But, the care team's eagerness to improve care is the key of improving quality of care in any CF centre. A focus for adjusting care to the highest standard and measuring its impact on outcomes should be a key goal for every CF team.

The last decades have influenced a need for rethinking about Infection Control recommendations in public health in general, justified in development of diagnostic and treatment improvement with better patient outcome. But, at the same time a need for change of adaptation to new or modified routines in daily practice, which affect knowledge and attitude among health care professionals, and finally patients and relatives. In a recent publication (30) authors point out that many studies have documented the necessity of understanding the route and mechanism behind cross infection between people with CF. Reducing this risk of these potentially harmful pathogens will likely be a benefit for patients with reduced morbidity, and its consequences for treatment burden.

Understanding the concept of cross infection is of great importance for the design and construction of new CF Centres, with aim of reducing risk of cross-infection to a minimum, and thereby reduce treatment burden and costs (2,7,12-18,30). This is illuminated by the recent experience from UK with concern of indirect transmission between CF patients with multi-resistant pathogen, despite conventional cross-infection measurements (20).
It is known that adherence to health care guidelines is negatively affected by different barriers in health care practice such as access to, and understanding of the guidelines (9,11,12,27,28). As pointed out in the study by Garber (9) poor adherence to guidelines may reflect complex attitude barriers experienced by health care professionals. For the

present study it was decided to, instead of adherence, use a positive approach and focus on health professionals' awareness of knowledge, attitude and practice for CF infection control guidelines. Focusing on awareness harmonize better with to the theoretical framework with quality improvement, salutogenesis (factors creating health) and learning organisations in health care.

Infection Control in health care will apply to patients with known and unknown infections with the purpose of reducing risk of cross-infection among patients and health care professionals. Measurements as protective isolation of patients may be used for suspected or identified contagious pathogens, and for optimising availability for effective treatment as antibiotic. Experiencing practice of Infection Control is for most patients and relatives a short "once in a lifetime" experience with good patient outcome. But, for patients with lifelong colonisation as cystic fibrosis patients with affection of lungs and airways, this is a condition where different Infection Control routines will be applied dependent on type of pathogens identified. Infection Control guidelines differ between hospitals, specialist and community care, and several publications confirm patients' experiences of diverse infection control knowledge, attitude and practice (9,11,12,27,28).

Continuous improvement for CF Infection Control

The continuing collaborative work with meetings and dialogue around CF patients will promote professionals' skills, and awareness for quality improvement of CF Infection Control and Hygiene Regimen – as demonstrated in the publication by Elborn (7) and Schechter (3): Empowering health care professionals, patients and relatives, user involvement, and collaboration and networking. By this support the guidelines and recommendation for application to daily practice, and patients education programme will be improved. Collaboration with patients and relatives ensures the best CF Infection Control at home. Infection Control is regarded as a cornerstone in CF care, and the importance of health care professionals, patients and families awareness of CF Infection Control guidelines is essential for reducing risk of cross-infection between CF patients in hospital care (table 7).

Evidence-based medicine has demonstrated contribution of CF hygiene regimen and infection control recommendations to improved patient care and disease outcome for cystic fibrosis (1-3,4,7,12,13,16,17,27-33,37,38,60-62). Close liaison is needed between the CF inter-professional team, microbiologists and infection control teams, and the importance of education for patients, their families and CF health care professionals was stressed, as their support is essential to the success of cross-infection control policies (32, 63). Several studies of experience and perception of practical Infection Control have visualised lack of knowledge, and concern about strict hygiene regimen with isolation and segregation at hospital (10,63-68).

A recent study (6) revealed that many CF patients and families are aware of the Infection Control guidelines, but few had discussed them more than once with their CF team. These findings illuminate the importance of engaging patients and their families in regular discussions about Infection Control that address questions and concerns including the potential impact of Infection Control on health and wellbeing. This KAP survey supports these results. Clinical practice is dependent on scientific evidence as well as expert opinions, resulting in differences of practice on a national, Scandinavian and international level – well known for patients with shared care.

Successful strategies for improvement of CF Centre care was implemented by the US CF Foundation in collaboration with CF health care professionals, and with use of data from CF registries. Learn from the best CF Centre care, and make necessary changes (3,60-62). A change of focus, from stressful CF Centre comparison situations, to a focus on learning from evidence-based measurements of best patient care that promote best patient care, diseases outcome, and cost benefit for health care. This is corresponding to the initiative to Nordic Ministerial Board taken by the CF Associations in Denmark, Sweden and Norway for an "openness of care strategies and patient outcome results between the Scandinavian CF Centres (44).

Table 7: Recommendations for use in healthcare and non-healthcare settings – preventive and protective Infection Control principles for Cystic Fibrosis.

Preventive and protective Infection Control principles for Cystic Fibrosis – for healthcare & non-healthcare settings	
Principles	*Comments*
Treat all CF patients the same; assume that all patients harbour potentially transmissible pathogens.	Knowledge of respiratory pathogen status may be inaccurate if patients have newly acquired a microorganism or if detection is suboptimal in the clinical microbiology laboratory.
Practice respiratory hygiene.	All patients should practice respiratory hygiene in healthcare and non-healthcare settings.
Practice hand hygiene.	All staff, patients, and families should practice hand hygiene in healthcare and non-healthcare settings.
Reduce contamination of environmental sources in the healthcare setting.	Provide supplies to frequently clean high touch items and horizontal surfaces in CF clinics and pulmonary function testing laboratories.
Appropriate cleaning and disinfection of home nebulisers.	Perform observations and nebuliser cleaning, provide two complete nebuliser set, and implement booster education to facilitate this practice.
Original table from "Infection prevention and control in cystic fibrosis" (Saiman 2011)	

CF teams assessment to guidelines and recommendations are highlighted as strategies for improvement of CF care, and implementing clinical practice of highest standard could be as:

Improving knowledge:

- Apply educational programmes on a regular basis and update knowledge for patients and relatives; as part of annual CF control.
- Apply educational programmes and specialist meetings for CF health care professional, as introduction to new colleagues and updating the experienced CF professionals.
- Apply annual meetings with CF Patient Association; for exchange of experiences and issues for improvement.

Improving attitude:

- Apply regular clinical meetings between involved health care professionals; as CF specialist team (paediatric, adolescent and adult), hospital team, microbiology team, infection team, infection control team, transplant team.
- Apply regular clinical meetings between involved health care professionals in shared care (specialist and community care), for exchanging experiences and harmonising care.
- Apply regular meetings with CF patients with strict Hygiene Regimens at hospital and non-healthcare settings – for exchange of experiences and issues for improvement.

Improving practice:

- Apply use of microbial monitoring and CF infection control recommendation as a logistic tool for best CF patient administration and hospital care; as integrated (coordinated) care pathway, single rooms at in- and out-patient clinic, harmonised hygiene regimen for patient, relatives and healthcare professionals.
- Apply information of individual CF Hygiene Regimen as Critical Information in Patient Medical Journal; to avoid risk of cross-infection between patients, and induced hospital infection from contaminated equipment.
- Apply strict hygienic routines for use of hospital respiratory equipment for CF patients; for inhalation therapy recommended use of private inhalation compressor and devices; or only sterilised hospital devices.

CF is defined as a rare disease, and patients experiences with a need for improved awareness of knowledge, practice and collaboration in social- and health care services are documented. CF health care is challenged by shared care at all levels within interprofessional work, and studies has demonstrated improvement in care by empowering health care professionals, patients and families with user involvement, collaboration and networking. Implementation of preventive and protective Infection Control principles for CF health care is recommended for an achivement of a high standard of CF Infection Control, followed by measuring outcome on patients disease development and health care practice – and a continuous judgement for changes to improve CF health care.

Future studies

Future studies of experience and awareness of CF Infection Control policies by patients and relatives would be important for further improvement of CF patient care, with use of qualitative and quantitative methods.

Also, of interest for improvement of CF healthcare are studies of patient educational programmes including relatives and homecare settings, as for studies of educational programmes for CF healthcare professionals and of collaboration and innovation within CF healthcare professionals.

Follow-up studies of CF Infection Control based on result from CF registries annual reports for treatment and patient outcome of CF disease are of importance for quality improvement in CF care.

Limitations of the study

During the last years there has been an international development for Quality Improvement Strategies for Cystic Fibrosis, and Infection Control is one of the focused issues. Several guidelines and recommendations have been published, exemplified with Europe and USA, to improve standards of CF care (1-3, 12, 13, 16, 49).

Infection Control has proved to be a barrier for some CF Centres and their health care professionals, frequently with the change of CF hygiene regimen and by the comparison of data for treatment strategies and patient outcome in CF registries (9, 11, 14, 15, 18, 19, 60-63). Well-known challenges and barriers for surveys have been recognised for this study, and analyses and conclusions are based on the respondents representing this study population. One limitation of the present study is the low number of respondents.

Cystic fibrosis is a rare disease in Scandinavia and the numbers of health care professionals caring for the patients are few at each site, at centres as well as at local hospitals, challenging the possibility to perform statistical analysis. The generous number of questionnaires distributed and the fact that few of the team members not directly involved in the medical care responded low, and only partly explained the response rate. New team members may have hesitated to respond due to concerns regarding anonymity and by wishing not to make a bad impression for themselves and the local CF team if not giving the right answers.

There are national, international and local guidelines to adhere to and it is a challenge to keep these updated and the staff informed. The person-to person education in clinical practice is of major importance as revealed by the good results on the “know how” part of this study while the knowledge of the theoretical background, “the know why” was lower.

Conclusion

This survey of knowledge, attitude and practice of hygiene regimens and Infection Control among health care professionals at the Scandinavian CF Centres and the Norwegian CF Satellite Teams has provided valuable information.

The SCFC respondents have experience from a larger CF patient population with hospital care challenges, clinical risks, and individual prevention of cross-infection between CF patients. The interprofessional teams consist of a number of health care professionals representing different professions and experience from clinical care. SCFC respondents demonstrate a high level of knowledge, attitude and practice on most guideline and survey components.

The NCFST respondents have experience from a relatively small number of CF patients, followed by similar challenges, risks, and preventive Infection Control measures for the few patients in their hospital care. The respondents represent core team professions as doctors, nurses and physiotherapists. NCFST respondents demonstrate a moderate to high level of knowledge, attitude and practice on most guideline and survey components.

A key finding was the high level of awareness of outcome expectancy for all selected guideline components, in contrast to the more moderate level of awareness of familiarity both for SCFC and NCFST respondents. Items with close connection to practical care and medical treatment seems to have a high awareness from respondents from both parts of the study, and the NCFST achieved very high scores for some clinically important guidelines and survey components. For both study parts of the KAP survey the awareness for knowledge was lower than for practice.

Infection Control is regarded as a cornerstone in CF care, and the importance of health care professionals’ awareness of CF guidelines is essential for reducing risk of cross-infection between CF patients in hospital care. Education of patients and families of practical Infection Control measures in home care, and recommendations for behaviour in health- and non-healthcare settings contributes to patients individual infection status and reduction of cross-infection between CF patients.

This study has revealed good knowledge of Infection Control measures in general, but also a need for continuous collaboration and education of written guidelines of CF Infection Control for improvement of CF health care professonals KAP, and for CF patients outcome.

Acknowledgements

To all of you who participated in this survey, and shared with me your knowledge, attitude and practice within CF Infection Control. By this collaboration we contribute for improvements of CF health care.

To my recommended supervisor from Gothenburg, Marita Gilljam, lung physician working with adults with cystic fibrosis, and with a PhD on the same disease. I am very grateful with all the effort, support and practical help from Marita, and without her this master project had stopped. Her professional knowledge and experience from working with the disease made all discussions easier, there was no need for long explanations about cystic fibrosis infection control.

To my centre leader, and colleague for more than 30 years, Olav Trond Storrøsten – we agreed at last, and your support and interest have been very inspiring. It was you who wanted this subject, and here it is!

To my centre colleagues, Berit Skraastad, Jorunn Homme and Egil Bakkeheim – with your support my education at NHV was made possible.

To my lovely family; my husband Arne Kristian and our children Johanne and Halvard. Always positive and supporting me, even much homework and my many travels for courses at NHV campus.

To the Norwegian Association of Cystic Fibrosis and all patients with CF and their families – you have so openly shared experiences and challenges of living with CF, in- and outside hospital. This is the most valuable learning to CF nurse activities.

And, to all of you at NHV; teachers, employees and students – my best years at school ever!

References

1 Kerem E, Conway S, Elborn S, Heijerman H. For the Consensus Committee. Standards of care for patients with cystic fibrosis: A European consensus. Journal of Cystic Fibrosis *2005; 4: 7-26*

2. Saiman L, Siegel J. The Cystic Fibrosis Foundation Consensus Conference on Infection Control Participants. Infection control recommendations for patients with cystic fibrosis: Microbiology, important pathogens, and infection control practices to prevent patient-to-patient transmission. American Journal of Infection Control, May 2003 (Vol. 31, Issue 3, Pages S6-S62)

3. Schechter, M.S., Guiterrez, H.H. 2010. Improving the quality of care for patients with cystic fibrosis. Journal of Cystic Fibrosis.

4. Knudsen PK, Olesen HV, Høiby N, Johannesson M, Karpati F, Laerum BN, Meyer P, Pressler T,Lindblad A; Scandinavian CF Study Consortium (SCFSC). Differences in prevalence and treatment of Pseudomonas aeruginosa in cystic fibrosis centres in Denmark, Norway and Sweden. J Cyst Fibros. 2009 Mar;8(2):135-42.
5. Lannefors L, Lindgren A. Demografic transition of the Swedish cystic fibrosis community-results of modern care. Respir Med. 2002 Sep;96(9):681-5.
6. Olesen HV, Pressler T, Hjelte L, Mared L, Lindblad A, Knudsen PK, Laerum BN, Johannesson M; Scandinavian Cystic Fibrosis Study Consortium. Gender differences in the Scandinavian cystic fibrosis population. Pediatr Pulmonol. 2010 Oct;45(10):959-65. doi: 10.1002/ppul.21265.
7. Elborn JS, Hodson M, Bertram C. Implementation of European standards of care for cystic fibrosis-control and treatment of infection. J Cyst Fibros. 2009 May;8(3):211-7. doi: 10.1016/j.jcf.2009.03.001
8. A guide to developing knowledge, attitude and practice survey. http://www.stoptb.org/assets/documents/resources/publications/acsm/ACSM_KAP%20GUIDE.pdf
9. Garber E, Desal M, Zhou J, Alba L, Angst D, Cabana M, Saiman L and the CF Infection Control Study Consortium. Barriers to Adherence to Cystic Fibrosis Infection Control Guidelines. Pediatric Pilmonoloy 43:900-907 (2008).
10. Zhou J, Garber E, Saiman L. Survey of infection control for patients with cystic fibrosis in the United States. Am J Infect Control. 2008 Apr;36(3):220-2. doi: 10.1016/j.ajic.2007.05.009.
11. Saiman L, Garber E. Infection control in cystic fibrosis: Barriers to implementation and ideas for improvement. Current Opinion in Pulmonary Medicine, 2009.
12. Saiman L, MacDonald N, Burns JL, Hoiby N, Speert DP, Weber D. Infection control in cystic fibrosis: Practical recommendations for the hospital, clinic, and social settings. American Journal of Infection Control, October 2000 (Vol. 28, Issue 5, Pages 381-385)
13. Saiman L, Siegel J. Infection Control in Cystic Fibrosis. Clinical Mikcrobiology Reviews, Jan. 2004, p. 57-71 http://www.ncbi.nlm.nih.gov/pmc/articles/PMC321464/pdf/0040.pdf
14. Conway S.: Segregation is good for patients with cystic fibrosis. Journal of Royal Social Medicine 2008: 101: S31-S35 http://jrsm.rsmjournals.com/content/101/Supplement_1/31.full.pdf+html
15. Geddes D: Segregation is not good for patients with cystic fibrosis. Journal of Royal Social Medicine 2008: 101: S36-S38. http://jrsm.rsmjournals.com/content/101/Supplement_1/36.full.pdf+html
16. Döring G, Høiby N for the Consensus Study Group: Early intervention and prevention of lung disease in cystic fibrosis: a European consensus. Journal of Cystic Fibrosis 2004; 3: 67-91
17. Siegel JD, Rhinehart E, Jackson M, Chiarello L, Health Care Infection Control Practices Advisory Committee. 2007: Guideline for Isolation Precautions: Preventing Transmission of Infectious Agents in Health Care Settings. American Journal of Infection Control, December 2007 (Vol. 35, Issue 10, Pages S65-S164)
18. Colombo C, Littlewood J. The implementation of care in Europe: the state of art. J Cyst Fibros. 2011 Jun;10 Suppl 2:S7-15. doi: 10.1016/S1569-1993(11)60003-9. Review.
19. Saiman L. Infection prevention and control in cystic fibrosis. Curr Opin Infect Dis. 2011 Aug;24(4):390-5. doi: 10.1097/QCO.0b013e32834748ff. Review.

20. Bryant JM, Grogono DM, Greaves D, Fowerake J, Roddick I, Inns T, Reacher M, Haworth CS, Curran MD, Harris SR, Peacock SJ, Parkhill J, Floto RA: Whole –genome sequencing to identify transmission of Mycobacterium abscessus between patients with cystic fibrosis: a retrospective cohort study. Lancet, 2013 May 4;381(9877):1551-60. doi: 10.1016/SO140-6736(13)60632-7.
21. Eurodis. Rare Diseases Europe (2013). The Voice of Rare Disease Patients in Europe. http://www.eurordis.org/content/what-rare-disease
22. Rarelink. Nordisk lenkesamling og kontaktmuligheter for sjeldne og lite kjente diagnoser (2013). http://rarelink.no/index.jsp
23. Ågrenska, kompetenscentrum för sällsynta diagnoser (2013). http://www.agrenska.se/Nksd/
24. Helsedirektoratet. God helse – gode liv. Sjeldne tilstander (2013). http://www.helsedirektoratet.no/helse-og-omsorgstjenester/sjeldne-tilstander/Sider/default.aspx
25. Socialstyrelsen. Viden til gavn. Handicap. Sjeldne handicap (2013). http://socialstyrelsen.dk/handicap/sjaeldnehandicap/beskrivelser-af-diagnoser
26. Grue L. En vanskelig pasient? Sykehusene og pasienter med sjeldne medisinske tilstander [A difficult patient? The hospitals and the patients with a rare medical condition]. NOVA Rapport 11-2008. Oslo, Norway: NOVA _ Norwegian Social Research.
27. Fluge G, Ojeniyi B, Høiby N, Digranes A, Ciofu O, Hunstad E, Haanæs, OC, Storrøsten OT. Typing of Pseudomonas Aeruginosa strains in Norwegian Cystic Fibrosis patients. Clin Microbiol Infect. 2001;7:238-243
28. Meyer P, Johansson E, Welinder-Olsson C, Lindblad A, Hjelte L, Karpati F. Pseudomonas aeruginosa transmission at a winter camp in spite of rigorous precautions. J Cyst Fibrosis 2007;6(S28):114 http://www.sciencedirect.com/science/article/pii/S1569199307601040
29. E. Johansson, C. Welinder-Olsson, A. Lindblad, M. Gilljam, M. Johannesson, P. Meyer, L. Hjelte, F. Karpati. Genomic fingerprinting of *Pseudomonas aeruginosa* isolates from all Swedish CF Centres. A Scandinavian Cystic Fibrosis Study Consortium study *Journal of Cystic Fibrosis*, *Volume 6, Supplement 1*, *June 2007*, *Page S26.* http://www.sciencedirect.com/science/article/pii/S1569199307600952
30. Clifton IJ, Peckham DG. Defining routes of airborne transmission of Pseudomonas aeruginosa in people with cystic fibrosis. Expert Rev Respir Med. 2010 Aug;4(4):519-29. doi: 10.1586/ers.10.42. Review.
31. Armstrong DS, Nixon GM, Carzino R, Bigham A, Carlin JB, Robins-Browne RM, Grimwood K. Detection of a widespread clone of Pseudomonas aeruginosa in a pediatric cystic fibrosis clinic. Am J Respir Crit Care Med. 2002 Oct 1;166(7):983-7. http://ajrccm.atsjournals.org/content/166/7/983.full.pdf+html
32. Jones AM, Webb AK. Recent advances in cross-infection in cystic fibrosis: Burkholderia cepacia complex, Pseudomonas aeruginosa and Pandoraea spp. Journal of the Royal Society of Medicine Supplement No 43 Volume 96 2003 http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1308790/pdf/12906328.pdf
33. Blau H., Mussaffi H., Zahav MM., Prais D., Livne M., Czitron BM., Cohen HA. Microbial contamination of nebulizers in the home treatment of cystic fibrosis. Child care, health and development (2006) 33, 4, 401-495.

34. Zuckerman JB, Zuaro DE, Prato BS, Ruoff KL, Sawicki RW, Quinton HB, Saiman L; Infection Control Study Group. Bacterial contamination of cystic fibrosis clinics. J Cyst Fibros. 2009 May;8(3):186-92. doi: 10.1016/j.jcf.2009.01.003.
35. Filstad C. Forskning på jobben, ikke på kurs. Forskning.no (2012). http://www.forskning.no/artikler/2007/mai/1178607732.83
36. Blåka G, Filstad C. Læring i helseorganisasjoner. Cappelen Akademiske Forlag 2007 http://www.cappelendammundervisning.no/undervisning/product-detail.action?id=125286&query=filstad+bl%C3%A5ka&richList=true
37. Cystisk fibrose nr 4-2005. Krydsinfektion. http://www.cff.dk/infomateriale/cfbladet/cfbladetpdf/cfblad20054.pdf
38. Fredriksen B, Koch C, Høiby N. Changing epidemiology of Pseudomonas aeruginosa infection in Danish cystic fibrosis patients (1974-1995). Pediatr Pulmonol. 1999 Sep;28(3):159-66. . http://onlinelibrary.wiley.com/doi/10.1002/(SICI)1099-0496(199909)28:3%3C159::AID-PPUL1%3E3.0.CO;2-1/pdf
39. Folkehelseinstituttet. www.fhi.no – for et friskere folk (2013). http://www.fhi.no
40. Statens Serum Institutt (2013). http://ssi.dk
41. Smittskyddinstitutet (2013). http://www.smittskyddsinstitutet.se
42. Grut L, Kvam MH. Facing ignorance – people with rare disorders and their experiences with public health and welfrare services. Scandinavian Journal of Disability Research, 2012.
43. Ahgren, B. 2010. Dissolving the Patient Bermuda Triangle. International Journal of Care Pathways; 14: 137-141. http://ijcp.rsmjournals.com/content/14/4/137.abstract
44. Norsk forening for cystisk fibrose. Ønsker åpenhet om behandlingsdata for CF pasienter (2012). http://cfnorge.no/aktuelt/arkiv/2011/onsker-apenhet-om-behandlingsdata-for-cf-pasienter/
45. Antonovsky, Aaron ”Hälsans mysterium”. http://www.bokus.com/bok/9789127110274/halsans-mysterium/
46. Lindstrom B, Eriksson M. Salutogenesis. J Epidemiol Community Health 2005;59:440-442 doi:10.1136/jech.2005.034777
47. Lindstrom, Bengt, Eriksson, Monica. Red. The Hitchhiker's Guide to Satutogenesis. Salutogenic pathway to health promotion. Folkhälsan Researh Center, Health Promotion Research. Resaerch Report 2010:2. http://www.salutogenesis.hv.se/swe/Publikationer.82.html
48. Nasjonalt kunnskapssenter for helsetjenesten. En beskrivelse av utviklingen av modell for kvalitetsforbedring, og hvordan den kan bruks i praktisk forbedringsarbeid. Notat fra Kunnskapssenteret januar 2013. Notat: ISBN 978-82-8121-500-9. www.kunnskapssenteret.no
49. McPhail, G.L., Weiland, J., Acton, J.D., Ednick, M., Chima, A., VanDyke, R., Fenche,l M.C., Amin R.S., Seid, M. 2010. Improving Evidence-Based Care in Cystic Fibrosis Through Quality Improvement. Arch Pediatr Adolesc Med/Vol 164 (No. 10) Oct.
50. Peter M Senge, (1997) "THE FIFTH DISCIPLINE", Measuring Business Excellence, Vol. 1 Iss: 3, pp.46 – 51 Doi: 10.1108/eb025496.
51. Reeves S, Lewin S, Espin S, Zwarenstein M. Interprofessional Teamwork for Health and Social Care. Wiley-Blackwell 2010. http://eu.wiley.com/WileyCDA/WileyTitle/productCd-1405181915.html

52. Axelsson, S.B., Axelsson, R. 2009. From territoriality to altruism in interprofessional collaboration and leadership. Journal of Interprofessional Care, July; 23(4): 320-330. http://informahealthcare.com/doi/pdf/10.1080/13561820902921811
53. Willumsen, E. 2009 " Differensiering og integrering – dynamikken i tverrprofesjonelt samarbeid?" i Tverrfaglig samarbeid i praksis og utdanning, eds. Willumsen, E., Universitetsforlaget, Oslo, side 35-51.
54. Mykland S. Bør tåle en konflikt på jobben. Forskning.no (2012). http://www.forskning.no/artikler/2011/oktober/303216
55. WHO. Ottawa Charter for Health Promotion 1986. http://www.who.int/healthpromotion/conferences/previous/ottawa/en/index.html
56. WHO. Infection control (2012). http://www.who.int/topics/infection_control/en/
57. WHO. Standard precautions in health care (2012). http://www.who.int/csr/resources/publications/EPR_AM2_E7.pdf
58. Center for Disease Control and Prevention (2012). http://www.cdc.gov/
59. Spørreundersøkelser. Kalkulasjon av en spørreundersøkelses pålitelighet (2013). www.spørreundersøkelser.no – kalkulator
60. Tiddens HA. Quality improvement in your CF Centre: taking care of care. J Cyst Fibros. 2009 Jun;8 Suppl 1:S2-5. doi: 10.1016/S1569-1993(09)60003-5.
61. Kraynack, N.C., McBride, J.T. 2009. Improving Care at Cystic Fibrosis Centers through Quality Improvement. Seminars in Respiratory and Critical Care Medicine/Volume 30, Number 5.
62. Brown V, Weber D, Brooks B, Adams T, Featherstone B. Implementation of the Cystic Fibrosis Foundation infection control guidelines at a university healthcare system: A multidisciplinary approach requiring continuous quality improvement. *American Journal of Infection Control, June 2005 (Vol. 33, Issue 5, Pages e158-e159)*
63. Aavitsland P. For strenge MRSA-tiltak gir lidelse – fagkronikk.Sykepleien, 1-2009, side 68-69
64. Duff AJA: Psychological consequences of segregation resulting from chronic Burkholderia cepacia infection in adults with CF. Thorax 2002 57: 756-758
65. Griffiths AL, Armstrong D, Carzino R, Robinson P: Cystic Fibrosis patients and families support cross infection measures. Eur Respir J 2004: 24: 449-452 http://erj.ersjournals.com/content/24/3/449.full.pdf+html
66. Russo K, Donnelly M, Reid AJM.: Segregation – the perspectives of young patients and their parents. Journal of Cystic Fibrosis 5 (2006) 93-99
67. Ullrich G, Wiedau S, Schulz W, Steinkamp G: Parental knowledge and behaviour to prevent environmental P. aeruginosa acquisition in their child with CF. Journal of Cystic Fibrosis 7 (2008) 231-237.
68. Miroballi Y, Garber E, Jia H, Zhou JJ, Alba L, Quittell LM, Angst D, Cabana M, Saiman L; CF Infection Control Study Consortium. Infection control knowledge, attitudes, and practice among cystic fibrosis patients and their families. Pediatr Pulmonol. 2012 Feb;47(2):144-52. doi: 10.1002/ppul.21528.

Appendices

1. Glossary

Ability	Capacity, potential, facility
Adherence	Awareness, understanding, knowledge
Airborne transmission	Transmission of infectious agents by dissemination of either droplet nuclei (small-particle of evaporated droplets) or dust particles containing the infectious agent. Ex include M. Tuberculosis, measles and varicella-zooster viruses.
Antiseptic agents	Antimicrobial substances applied to skin to reduce amount or level of microbial flora. Ex include alcohols, chlorine, etc.
Antiseptic hand wash	Washing hands with water and soap or other detergents containing an antiseptic agent.
Awareness	Understanding, knowledge, familiarity
Cross infection	The transfer of infection, especially to a hospital patient with a different infection or between, different species of animal or plant (from Oxford Dictionary of English)
Disinfectant	A chemical or physical agent that destroys infectious pathogens on environmental surfaces or medical devices but may not kill bacterial spores.
Disinfection	The destruction of pathogenic and other kinds of microorganisms by thermal or chemical means. This is a less lethal process than sterilization because it destroys most recognized pathogenic microorganisms, but not all microbial forms such as bacterial spores.
Droplet transmission	Person-to-person spread of infectious agents by large particle droplets generated primarily during coughing, sneezing, or talking, and during the performance of certain procedures such as suctioning or bronchoscopy.
Contact transmission	• Direct contact transmission: Direct body surface-to-body surface physical transfer of an infectious agent(s) between a susceptible host and an infected or colonized person. Ex include touching hands contaminated with secretions. • Indirect contact transmission: Contact of a susceptible host

	with an intermediate object that has been contaminated with secretions containing an infectious agent. Ex include respiratory equipment, eating utensils.
Environment	Refer to a reservoir (e.g. water, sinks, soil, etc.) or an environmental surface or patient care item that can be contaminated with infectious materials.
Guideline	Recommendation, instruction, standard, measure
Hand hygiene	A general term to either hand washing, antiseptic hand wash, antiseptic hand rub, or surgical hand antisepsis.
Hand washing	Washing hands with plain (nonmicrobial) soap and water.
Intervention	A change(s) in practice implemented in response to identification of a clinical problem that is associated with an undesirable patient outcome. Interventions are identified from evidence in the medical literature or strong theoretical rationale-Ongoing surveillance is essential to ascertain the safety and effectiveness of the newly implemented intervention.
Personal protective equipment	Materials used to protect healthcare workers from acquiring infection when exposed to blood or body fluids during patient care activities and to prevent transmission of pathogens to others. Ex include gloves, gowns, masks, etc.
Recommendation	Advice, guidance, suggestions
Standard precautions	Apply to all patients, regardless of diagnosis or presumed infection status. Standard precautions combine the principles of universal substance isolation and consider all blood, body fluids, secretions, and excretions except sweat, non-intact skin, and mucous membranes to have the potential for containing transmissible infectious agents.
Segregation	Separation of patients from one another (originally term for group segregation).
Sterilisation	The complete destruction of ALL forms of microbial life, including fungal and bacterial spores. Sterilization is accomplished in healthcare settings by either physical or chemical processes.
Sufficient	Enough, adequate
Transmission-based precautions	Apply to patients with documented or suspected infection with highly transmissible or epidemiologically important infectious

	agents for which precautions in addition to standard precaution are required to interrupt transmission. Categories include: Contact, droplet, airborne, and protective environment or a combination when a disease has multiple routes of transmission.
Time to educate	Amount of time to teach (students, patients)
Time for education	Amount of time for training, in-service education and training
Adaptet from original glossary "Infection control guidelines for patients with CF" (Saiman 2003)	

2. Enquiry for survey participation – copy of e-mail

To Center Leaders at the Scandinavian Cystic Fibrosis Centres in Copenhagen, Aarhus, Lund, Gothenburg, Stockholm, Uppsala, Bergen and Oslo

Hygiene Regimen and Infection Control At the Scandinavian CF Centres – enquiry for survey participation

I am a student at the Nordic School of Public Health in Gothenburg, and now working with my master project – a survey to multidisciplinary team members at the Scandinavian CF centres.

Aim of the study is "Hygiene Regimen and Infection Control in practice in Cystic Fibrosis (CF) Care – Knowledge, recommendations and implementation at the Scandinavian CF Centres by the multidisciplinary team members."

The importance of infection control and good standards of hygiene is well known within the CF community. Cross infection between patients is documented at several CF centres, and is a risk factor for the progression of lung disease with multiresistant bacterias at hospitals and summercamps..

The study will give information of knowledge, recommendations and implementation of infection control within multidisciplinary professionals at the Scandinavian CF-centres – professionals who have contact with patients during consultations or treatment.

A questionnaire will be posted to the individual professionals at the CF multidisciplinary team - using a modified version of KAP survey previously used in CF (Garber & al, 2008).

Collected data will be of importance for the different findings of prevalence in infections shown in the SCFSC's study from 2004. Information will be useful for evaluation of true practice and need for change.

My supervisors are:
Marita Gilljam, MD/specialist in pneumology/dr.med., Sahlgrenska sjukhus, Gothenborg.
Olav-Trond Storrøsten, MD/leader of the Norwegian Centre for Cystic Fibrosis, Oslo University Hospital – Ulleval.

I plan for study start in January-February 2011, and hope for your participation to my study.

Kindly
Ellen Julie Hunstad
Registrated Nurse / Clinical Nurse Specialist/MPH student
Norwegian Center for Cystic Fibrosis, Oslo University Hospital – Ulleval Hospital
Phone: + 47 23 01 55 90 Email: llhu@uus.no

3. Questionnaire

	-			

Hygiene regimen and Infection control at the Scandinavian Cystic Fibrosis Centres

KAP survey to CF multidisciplinary care team

Ellen Julie Hunstad
RN/CNS/DPH/DIC
Nordic School of Public Health
Norwegian Center for Cystic Fibrosis

I appreciate your time, assistance and honesty in completing this questionnaire.
<u>It will take about 20 minutes to complete.</u>
All responses are confidential. No staff identifiers will be collected. Only your site will be identified by a unique study number and only aggregate data will be analyzed and reported.
This questionnaire has been adapted from original survey by Lisa Saiman & Elisabeth Garber 2008

Knowledge, Attitude & Practice Questionnaire for Scandinavian Cystic Fibrosis Multidisciplinary Team

Mark with cross the <u>one</u> answer that best applies to you.

1. Which of the following best describes you?
   - ❑ Member of the CF multidisciplinary specialist care team
   - ❑ Member of the hospital care team at in patient clinic / out patient clinic

2. Which of the following best describes your profession?
   - ❑ Medical Doctor
   - ❑ Nurse
   - ❑ Respiratory therapist / physiotherapist
   - ❑ Dietition / nutritionist
   - ❑ Psychologist
   - ❑ Social worker
   - ❑ Other: ________________________________

3. What percentage of your time is spent in CF-related activities?
   - ❑ Very little of my time (<10%)
   - ❑ Up to half of my time (10-50%)
   - ❑ More than half of my time (50-75%)
   - ❑ Most of my time (75-100%)

4. Do you have contact with? [**Please check all answers that apply**]

	Yes	No
Adults with CF	❑	❑
Children with CF	❑	❑
Newborn screening clinic for CF	❑	❑
CF transplant recipients	❑	❑

5. How many years have you been working in CF-care related activities?

   ____

Please indicate if you agree or disagree with the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
6. All CF patients have potentially transmissible pathogens in their respiratory tract secretions.	❑	❑	❑	❑	❑

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
7. Quarterly cultures of the respiratory tract are useful for CF patients.	❑	❑	❑	❑	❑

Please indicate if you agree or disagree with the following statements:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
8. During hospitalizations CF patients should not socialize together.	❑	❑	❑	❑	❑

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
9. Cleaning and disinfecting nebulizers used in the home will prevent acquisition of pathogens.	❑	❑	❑	❑	❑

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
10. Cleaning exam rooms in the CF clinic between patients will decrease the transmission of pathogens.	❑	❑	❑	❑	❑

Please *estimate* the following percentages:

	None	< 25%	25-50%	51-75%	>75%
11. What <u>percentage</u> of CF patients at your center have cultures of the respiratory tract performed every 4-6 weeks?	❑	❑	❑	❑	❑
Comments:					

	None	< 25%	25-50%	51-75%	>75%
12. What <u>percentage</u> of CF patients are discouraged from socializing together during hospitalization?	❑	❑	❑	❑	❑
What kind of microbiological organism?					

	None	< 25%	25-50%	51-75%	>75%
13. What <u>percentage</u> of CF patients and their families do <u>you</u> educate to					

practice proper hand hygiene?	❑	❑	❑	❑	❑
If not you, who does this?					

Please *estimate* the following percentages:

14. What <u>percentage</u> of CF patients are instructed by <u>you</u> to clean and disinfect their home nebulizers?	None	< 25%	25-50%	51-75%	>75%
	❑	❑	❑	❑	❑
If not you, who does this?					

15. What <u>percentage</u> of exam rooms are cleaned between patients in the CF clinic?	None	< 25%	25-50%	51-75%	>75%
	❑	❑	❑	❑	❑

How confident are you in your team's ability to accomplish the following:

16. Obtain cultures of the respiratory tract from CF patients every 4-6 weeks.	Not confident	Somewhat confident	Moderately confident	Very confident	Extremely confident
	❑	❑	❑	❑	❑

17. Secure a single patient room for your CF patients infected with multidrug-resistant organisms.	Not confident	Somewhat confident	Moderately confident	Very confident	Extremely confident
	❑	❑	❑	❑	❑

18. Ensure that exam rooms are cleaned between CF patients.	Not confident	Somewhat confident	Moderately confident	Very confident	Extremely confident
	❑	❑	❑	❑	❑

19. Educate CF patients and their families on proper hand hygiene.	Not confident	Somewhat confident	Moderately confident	Very confident	Extremely confident
	❑	❑	❑	❑	❑

20. Educate CF patients and their families to clean and disinfect	Not confident	Somewhat confident	Moderately confident	Very confident	Extremely confident

home nebulizers.	❑	❑	❑	❑	❑

How confident are you in your team's ability to accomplish the following:

21. Prevention of socialization between CF patients during hospitalization.	Not confident	Somewhat confident	Moderately confident	Very confident	Extremely confident
	❑	❑	❑	❑	❑
Comments:					

How would you rate the effect of the following practices on improving patients' outcomes based on your experience?

22. Collecting cultures of the respiratory tract from CF patients every 4-6 weeks.	No effect	Minimal effect	Moderate effect	Large effect	Extremely Large effect
	❑	❑	❑	❑	❑
Comments:					

23. Avoiding socialization with other CF patients during hospitalization.	No effect	Minimal effect	Moderate effect	Large effect	Extremely Large effect
	❑	❑	❑	❑	❑
Comments:					

24. Performing appropriate hand hygiene by CF patients.	No effect	Minimal effect	Moderate effect	Large effect	Extremely Large effect
	❑	❑	❑	❑	❑
Comments:					

25. Cleaning and disinfecting the home nebulizers of CF patients.	No effect	Minimal effect	Moderate effect	Large effect	Extremely Large effect

	❑	❑	❑	❑	❑

	No effect	Minimal effect	Moderate effect	Large effect	Extremely Large effect
26. Cleaning exam rooms between CF patients.	❑	❑	❑	❑	❑

Please rate the significance of <u>each</u> factor on your ability to:

27. Collect cultures of the respiratory tract from CF patients at your center every 4-6 weeks.

	Not Significant	Slightly Significant	Moderately Significant	Very Significant	Extremely Significant
a) Lack of time during clinic visits	❑	❑	❑	❑	❑
b) Lack of support staff	❑	❑	❑	❑	❑
c) Lack of administrative support	❑	❑	❑	❑	❑
d) Lack of financial reimbursement	❑	❑	❑	❑	❑
e) Lack educational material for patients	❑	❑	❑	❑	❑
f) Other: (please specify)	❑	❑	❑	❑	❑

28. Discourage your CF patients from socializing together during hospitalization.

	Not Significant	Slightly Significant	Moderately Significant	Very Significant	Extremely Significant
a) Lack of time to educate	❑	❑	❑	❑	❑
b) Lack of support staff	❑	❑	❑	❑	❑
c) Lack of administrative support	❑	❑	❑	❑	❑
d) Lack of space	❑	❑	❑	❑	❑
e) Lack of educational material for patients	❑	❑	❑	❑	❑
f) Other: (please specify)	❑	❑	❑	❑	❑

Please rate the significance of <u>each</u> factor on your ability to:

29. Educate CF patients and their families to practice proper hand hygiene while waiting in the CF clinic.

	Not Significant	Slightly Significant	Moderately Significant	Very Significant	Extremely Significant
a) Lack of time to educate	❑	❑	❑	❑	❑
b) Lack of support staff	❑	❑	❑	❑	❑
c) Lack of administrative support	❑	❑	❑	❑	❑
d) Lack of educational material	❑	❑	❑	❑	❑
e) Lack of in-service training for CF team	❑	❑	❑	❑	❑
f) Other: (please specify)	❑	❑	❑	❑	❑

30. Educate CF patients and their families to clean and disinfect their home nebulizer equipment.

	Not Significant	Slightly Significant	Moderately Significant	Very Significant	Extremely Significant
a) Lack of time for education	❑	❑	❑	❑	❑
b) Lack of support staff	❑	❑	❑	❑	❑
c) Lack of administrative support	❑	❑	❑	❑	❑
d) Lack of educational material	❑	❑	❑	❑	❑
e) Lack of in-service training for CF team	❑	❑	❑	❑	❑
f) Other: (please specify)	❑	❑	❑	❑	❑

Please rate the significance of <u>each</u> factor on your ability to:

31. Ensure that the exam rooms are cleaned between CF patients.

	Not Significant	Slightly Significant	Moderately Significant	Very Significant	Extremely Significant
a) Lack of time during clinic visit	❑	❑	❑	❑	❑
b) Lack of support staff	❑	❑	❑	❑	❑
c) Lack of administrative support	❑	❑	❑	❑	❑
d) Lack of educational material	❑	❑	❑	❑	❑
e) Lack of in-service training	❑	❑	❑	❑	❑
f) Other: (please specify)	❑	❑	❑	❑	❑

Please indicate your familiarity about infection control recommendations.

32. Do you know about the CF Foundation Infection control recommendations for patients with cystic fibrosis: Microbiology, important pathogens, and infection control practices to prevent patient-to-patient transmission 2003?	Yes	No	Not sure
	❑	❑	❑
If yes, where did you learn about it?			

33. Do you know about the European CF Society's Standards of care for Cystic Fibrosis 2005?	Yes	No	Not sure
	❑	❑	❑
If, yes where did you learn about it?			

34. Do you know about the Scandinavian CF Consortium Study Differences in prevalence and treatment of Pseudomonas aeruginosa in cystic fibrosis centres in Denmark, Norway and Sweden 2009?	Yes	No	Not sure
	❑	❑	❑
If yes, where did you learn about it?			

Please indicate your familiarity with the following aspects of the CF guidelines:

35. The overall contents of the CF guidelines.	Not familiar	Somewhat familiar	Very familiar
	❑	❑	❑

36. Recommendation for cultures of the respiratory tract every 4-6 weeks.	Not familiar	Somewhat familiar	Very familiar
	❑	❑	❑

37. Recommendation to teach CF patients <u>not</u> to socialize with other CF patients while hospitalized.	Not familiar	Somewhat familiar	Very familiar
	❑	❑	❑

	Not familiar	Somewhat familiar	Very familiar
39. Recommendation to educate patients and their families to practice proper hand hygiene.	❑	❑	❑

	Not familiar	Somewhat familiar	Very familiar
39. Recommendation to clean and disinfect home nebulizers after use.	❑	❑	❑

	Not familiar	Somewhat familiar	Very familiar
40. Recommendation to clean the exam room between CF patients.	❑	❑	❑

Please indicate your familiarity with the following aspects:

	Not familiar	Somewhat familiar	Very familiar
41. Change of infection control recommendations for your CF patients after the Scandinavian CF Consortium Study 2004 about differences between the CF centres?	❑	❑	❑
Comments:			

	Not familiar	Somewhat familiar	Very familiar
42. Change of infection control attitude for your CF patients after the Scandinavian CF Consortium Study 2004 about differences between the CF centres?	❑	❑	❑
Comments:			

	Not familiar	Somewhat familiar	Very familiar
43. Change of infection control practice for your CF patients after the Scandinavian CF Consortium Study 2004 about differences between the CF centres?	❑	❑	❑

Comments:

44. Do you have local/national CF infection control guidelines? If yes, which?

45. Are there any additional issues related to infection control in CF that you have comments on?

Thank you so much for your time and consideration. I really appreciate it. Please return the sealed envelope to the local research coordinator/nurse who will mail all envelopes from your center to me.

For questions please contact me by email: uxllhu@ous-hf.no

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