

Immigrants with heart failure

- A descriptive comparative study of symptoms, self care,
social support, care and treatment

Azar Hedemalm

Institute of Health and Care Sciences

Göteborg University



The Sahlgrenska Academy
at GÖTEBORG UNIVERSITY

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To all people suffering from an illness and its distress

ABSTRACT

It is acknowledged that cultural background affects illness experience, participation in the care or self-management of illness, little is presently known about the treatment patterns, symptoms, health care seeking and health outcomes among immigrants with heart failure (HF) in Sweden or other Scandinavian countries. **Aim:** This comparative, explorative thesis describes immigrants with HF regarding symptoms, self-care, social support, care and treatment, physical limitation and emotional state, as well as health outcomes, *e.g.*, readmissions and mortality, in comparison to Swedes. **Method:** The thesis has a descriptive and comparative design. The first study is an interview study exploring symptom recognition and health care strategies related to worsening of HF. The second and third studies of the thesis are retrospective record audits of patient records describing care and treatment of immigrant and Swedish patients with HF in a medical ward and at a nurse-led HF clinic. The fourth study is a descriptive study with group comparisons of changes from baseline to four month follow up, in symptoms, functional limitations, emotional status, social support and self-care measures over a four month period, from baseline to four-month follow-up. The study setting was a university hospital serving a large and diverse immigrant population. **Results:** A majority of the immigrant and Swedish patients sought health care for symptoms and signs, such as breathing difficulties, fatigue and swelling. In addition, equal numbers of patients in both groups were aware of their reluctance to seek care when symptoms and signs occurred, and gave diverse explanations for delays. However, twice as many immigrants as Swedes were unaware of the underlying reason for their illness and its connection with HF (I). Reviewed patient records revealed no significant differences between the groups regarding symptoms, diagnostic investigations, medical treatment, hospital stay and health outcomes, such as readmissions and mortality. Furthermore, records from both patient groups showed that functional status using the New York Heart Association classification was infrequently assessed and that documentation of provided HF information was lacking. The only significant between-group differences were that more immigrants were referred to the nurse-led HF clinic for a follow-up visit at discharge (II); fewer routine clinical parameters were assessed in immigrants; and fewer immigrants were scheduled for follow-up visits (III). No differences were seen between immigrants and Swedes regarding 4-month changes in symptoms and signs, physical functioning, social support, emotional status, or in health care seeking in response to certain symptoms. However, adherence to prescribed medications was significantly higher among immigrants, whereas significantly fewer immigrants reported that they had access to emotional support if needed (IV). **Conclusion and implication:** Although immigrant and Swedish patients with chronic heart failure were provided largely the same care and treatment, fewer immigrants were able to relate their symptoms to their condition when seeking acute care. Immigrants also reported higher adherence to prescribed medication and were more often referred to the nurse-led HF clinic by physicians at discharge from hospital, possibly with the expectation that the patients would receive more individualised care and follow up. Information about how and if patient education and counselling had been carried out was rarely documented in the patient records. Patient records should document performed assessments and interventions, which may improve communication between caregivers in different health care settings and consequently improve the efficiency of future care plans.

Keywords: Immigrant, heart failure, symptom, treatment, self care, physical and emotional state, social support, content analysis, patient records

ORIGINAL PAPERS

This thesis is based on the following studies (papers) which will be referred to in the thesis by Roman numerals (I-IV):

- I. Hedemalm, A., Schaufelberger, M., Ekman, I. Symptom recognition and health care seeking among immigrants and native Swedes with heart failure (*submitted*)
- II. Hedemalm, A., Schufelberger, M., Ekman, I. Equality in the care and treatment of immigrants and native Swedes - A comparative study of patients hospitalised for heart failure (*accepted 2007, The European Journal of Cardiovascular Nursing*).
- III. Hedemalm, A., Schaufelberger, M., Ekman, I. A review of records from follow-up visits for immigrant and Swedish patients at a heart failure clinic (*The European Journal of Cardiovascular Nursing 2007;6(3):216-222*)
- IV. Hedemalm, A., Schaufelberger, M., Ekman, I. A descriptive study of symptoms, physical limitation, emotional state, social support and self-care focusing immigrants and native Swedes. (*Manuscript*)

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ABBREVIATIONS

CHF	chronic heart failure
CVD	cardiovascular disease
CHD	coronary heart disease
ESC	European Society of Cardiology
EF	Ejection fraction
GP	general practitioner
HF	heart failure
HQoL	health-related quality of life
HAD	Hospital Anxiety and Depression
KCCQ	Kansas City Cardiomyopathy Questionnaire
LVEF	left ventricular ejection fraction
NYHA	New York Heart Association
QoL	quality of life

1. INTRODUCTION

My personal experience of being admitted to a hospital in a foreign country and not knowing what to expect or how to behave as a patient, may have given me a deeper empathy for patients of foreign origin. Research indicates that ethnic minorities perceive that they are not listened to or involved in decisions, that they are not respected and that they are sometimes unfairly treated (Blanchard and Lurie, 2004; Ngo-Metzger *et al.*, 2004). It has also been found that minorities tend to visit primary care more often (Shah *et al.*, 1996) and are less likely to be admitted to hospital (Quan *et al.*, 2006a), receive counselling, be scheduled for follow-up appointments (Derose and Baker, 2000; Ngo-Metzger *et al.*, 2004) and adhere to prescriptions (David and Rhee, 1998). Language barriers are associated with a risk for poor medical outcomes (Rivadeneira *et al.*, 2000), more use of diagnostic investigations (Hampers *et al.*, 1999), lower adherence to self-care measures (Karter *et al.*, 2000) and lower patient satisfaction (Baker *et al.*, 1998; Carrasquillo *et al.*, 1999; Liu *et al.*, 2007; Morales *et al.*, 1999). On the other hand, use of professional interpreters is associated with improved quality of clinical care (Karliner *et al.*, 2004).

I chose to study and compare immigrants with chronic heart failure since this patient group often seeks care and is readmitted to hospital several times a year. In addition to their troublesome symptoms, these patients also have to cope with language difficulties and limited knowledge about the health care system.

Migration

Migration is a phenomenon occurring in all nations at all times. According to Oxford English Dictionary, an immigrant is a person who comes to live permanently in a foreign country (Oxford Reference Online, 2007). In this thesis, the term immigrant refers to persons residing in Sweden who are born abroad and have a native language other than Swedish.

Reasons for migration are multifarious. Some individuals may migrate to escape political or religious persecution, while others do so to study, seek better employment, better their future or join other members of their family. During different decades, different ethnic groups have immigrated to Sweden for different reasons, with different educational and occupational backgrounds and from different age groups. Immigrants are a heterogeneous group of people who may face diverse experiences during or after migration, such as dealing with marginality, social isolation and alienation in a foreign culture. The only common denominator for immigrants to Sweden is that all have moved to Sweden. Immigration to Sweden has increased continuously since 1950. Currently, almost 20% of Swedish inhabitants originate from other ethnic backgrounds representing all areas of the world (Statistical Yearbook of Sweden, 2005). According to statistics from the Swedish Board of Migration, of the 65000 persons who immigrated to Sweden in 2005, 19 % were from Nordic countries, 34% came from other European countries and the remaining 47 % emigrated from other parts of the

world. First generation immigrants comprised 12.4 % of the immigrant population (Swedish Migration Board, 2005). Currently, the largest immigrant groups in Sweden are Scandinavians (Danes, Finns, Norwegian), followed by people from the former Yugoslavia and the Middle East (Iraq, Iran and Turkey).

Race, ethnicity, culture

The word race is not an adequate variable in comparative studies of differences between human populations. As the most of human gene variation falls within and not between populations, the term “*race*” remains a social construct with social meaning and influence on health, without having any biological or genetic basis (Rosenberg *et al.*, 2002). *Ethnicity* originates from the Greek word “ethnos” meaning people, usually non-Greeks or foreigners. Leininger, an American nurse-anthropologist, offers this definition: “... ethnicity refers to the social identity and past origins of a social group largely due to a language, religion and place of birth” (Leininger, 1995). She defines culture as “... the learned shared and transmitted knowledge of values, beliefs, norms and life ways of a particular group that guides an individual or group in their thinking, decisions and actions in a patterned way”. The word “race” is sometimes used as a synonym for ethnicity or as a label for minority groups. However, ethnicity includes three important aspects, i.e. cultural values, attitudes and behaviours that distinguish ethnic groups; subjective sense of ethnic identity; and experiences associated with minority status of the ethnicity. Other aspects of ethnicity are the political, economical and historical factors influencing the concept of ethnicity (Phinney, 1996). According to Helman, an American medical anthropologist, culture is “... a set of guidelines (both explicit and implicit) which an individual inherits as a member of a particular society, and which tells him how to view the world, and how to behave in it in relation to other people, to supernatural forces or gods, and to the natural environment. It also provides him with a way of transmitting these guidelines to the next generation - by the use of symbols, language art and ritual” (Helman, 2000).

Health and illness perspectives

Western society’s bio-medical model of health is based on the assumption that health is the absence of disease. Disease is assumed to be caused by changes in body structure and functioning. Consequently, the malfunctioning body can be repaired and replaced, as in a machine it is assumed that the disease can also be “repaired” by treatments. However, according to this health model, the subjective experience of the disease, namely illness, may remain unrelieved (Bowling, 2002). In the social model of health, scientists distinguish between the subjective perception of disease (illness/sickness) and the medical concept of it according to Bowling. While illness reflects a personal and social experience of health status represented as symptoms, disease is a physiological disturbance manifested as clinical signs (Eisenberg, 1977). Illness can only be identified through the individual’s self-reports and self-ratings of symptoms versus health (Twaddle and Nordenfelt, 1993). Within a holistic perspective, health should be related not only

to disturbances in physical functioning but also to social functioning and personal well-being (Eisenberg, 1977).

The meaning that people assign to illness and its manifestations as symptoms can have profound implications for the individual's response and wellbeing. The meaning is influenced by culture, gender, experience, learning and beliefs and these in turn influence the individual's assessment of sensations, *e.g.*, a symptom (Teel *et al.*, 1997). Illness represents culturally shaped reactions to a certain discomfort and this mirrors the way an individual perceives, experiences and copes with it (Andrews and Boyle, 2003). According to Sachs, dividing the body and mind is the great problem of our time, namely people suffering without having a disease. With the social being replaced by a biological being, the subjective feeling of illness related to social causes and relationships has been objectified and medicalised (Sachs, 1996). While biomedical science is concerned with manifest biomedical indicators (signs) of disease, causes and internal processes, in contrast patients are concerned about external manifestations of disease, *e.g.*, symptoms, body image, autonomy and social self (Loewe and Freeman, 2000). The individual who experiences illness expresses a feeling of discomfort as a symptom, which signals changes in normal functioning. The most common reason for seeking care among patients with HF is for symptoms (Patel *et al.*, 2007), which are subjective personal experiences influenced by the context (Dodd *et al.*, 2001). The cultural meaning of the symptom is based on cultural beliefs and systems, which belong to this context. Symptoms can be related to disease or treatment (Bennett *et al.*, 2000) and experienced symptoms may lead to decreased quality of life and increased risk for morbidity and mortality (Konstam *et al.*, 1995; Konstam *et al.*, 1996).

Research to date has not found obvious associations between improvement of symptoms and clinical parameters, *e.g.*, cardiac output, pulmonary artery pressure or pulmonary capillary wedge pressure (Shah *et al.*, 2002). Cultural understanding is needed in order to be able to move from viewing the patient primarily as the "disease" or the presentation of signs, to patient-centred care focussing both on signs and symptoms. When health professional partnerships are formed between patients and caregivers, patients feel valued in the health care process, receive more culturally appropriate care, are more comfortable and have greater understanding of the assessment/intervention (Hooper *et al.*, 2007).

Cardiovascular disease among immigrants

Cardiovascular disease (CVD) includes diseases of the circulatory system (heart and blood vessels), *e.g.*, high blood pressure, ischemic heart disease, valvular disease and cardiomyopathy. Foreign-born inhabitants have an increased risk of cardiovascular or coronary heart disease compared with native-born Swedes, even after adjusting for age, education level and employment (Gadd *et al.*, 2006; Gadd *et al.*, 2003; Gadd *et al.*, 2005a). Among these risk factors in Sweden are overweight/obese, inactivity and smoking (Gadd *et al.*, 2005b; Lindström and

Sundquist, 2001; Lindström and Sundquist, 2005). Swedish health research among immigrants is limited to a few epidemiological studies within CVD and diabetes.

Heart failure

In the elderly population, chronic heart failure (CHF) is a common syndrome with different aetiologies, *e.g.*, different cardiovascular diseases. It is an incurable chronic condition with disabling symptoms, often requiring complex regimens and significant lifestyle changes. A literature review shows that 220 000 Swedish inhabitants, *i.e.* 2 % of the population, suffer from CHF (Mejhert *et al.*, 2001). It is the most common cause of hospitalisation in patients over 65 years of age. These patients are at high risk for re-hospitalisation (Krumholz *et al.*, 1997); however, a recent study has shown that readmissions and mortality decreased between 1988 and 2000 in patients hospitalised for HF (Schaufelberger *et al.*, 2004). The total annual cost for patients with HF in Sweden is about 5.0-6.7 billion SEK, of which hospital care accounts for 47 %, medication 18%, examinations 6%, primary care 22% and nursing home 5% (Agvall *et al.*, 2005). None of the above studies reported results from subgroups of patients or from immigrants. Although the dominating symptoms and signs of CHF are fatigue, dyspnoea, and peripheral oedema, between 21 and 45 different symptoms have been reported (Nordgren and Sörensen, 2003; Patel *et al.*, 2007; Zambroski *et al.*, 2005). Bennett and co-workers reported a large number of troublesome physical and emotional symptoms related to HF and its treatment, such as tiredness, loss of concentration, memory and balance, chest pain, insomnia, difficulty bending over, weight loss, fear, depression, and sadness (Bennett *et al.*, 2000).

Management of chronic heart failure

The diagnosis of HF is based on symptoms, objective evidence of cardiac dysfunction and response to HF treatments. Severity of heart failure is graded by means of the New York Heart Association classification (NYHA), a tool assessing the occurrence of symptoms related to physical activity, and by ejection fraction (EF), measuring left ventricular dysfunction (Swedberg *et al.*, 2005). Neither the NYHA classification nor the EF reflect the patients' self-reported severity of HF, which might be influenced by patients' psychosocial status and other co-morbid medical conditions (Ekman *et al.*, 2005b; Ekman *et al.*, 2006).

Treatment goals are to prevent diseases leading to CHF, delay progression of the manifest condition, avoid hospitalisation, improve QoL and finally prolong survival. Among recommended strategies are general advice, non-pharmacological treatment and pharmacological therapy. The pharmacological treatment is complex in advanced stages of the disease and leads to polypharmacy. Studies on the treatment of patients with preserved systolic function are sparse. Hence, the recommended treatments below are for patients with CHF and decreased systolic function. According to ESC guidelines, recommended first choice treatment is either angiotensin-converting enzyme (ACE) inhibitors or, in ACE-intolerant patients, Angiotensin II receptor blockers. Angiotensin II receptor blockers also

prolong survival and reduce hospitalisations if added to other recommended treatments. In cases of manifest fluid overload, diuretics should be given in combination with ACE inhibitors. Beta-blockers are recommended for treatment of patients with mild, moderate and severe CHF. Aldosterone receptor antagonists are recommended to complement the above mentioned treatment, spironolactone in advanced HF (NYHA III-IV) and eplerenone to patients after myocardial infarction with mild to moderate symptoms (NYHA II-III) (Swedberg *et al.*, 2005).

Care and treatment of patients with heart failure

Patients with CHF are at particular risk of re-hospitalisation. According to the European Society of Cardiology (ESC) guidelines, the hospital readmission rate is 30-50 % within six months of discharge (Swedberg *et al.*, 2005). A comprehensive discharge planning is recommended in order to improve symptoms and reduce re-hospitalisations. ESC guidelines also recommend the use of a multi-disciplinary team approach, optimisation of medical therapy, early attention to signs and symptoms, individual education and counselling and inpatient and outpatient follow-ups. However, it is known if recommended diagnostic investigations and evidence-based treatments are underused or if there is a lack of structured follow-ups in patients with HF in internal medical units compared with cardiology units (Di Lenarda *et al.*, 2003).

HF guidelines derive primarily from clinical trials, which are not representative of the “real world”, *e.g.*, they often explicitly exclude elderly, women and ethnic/cultural minorities. In addition, patients participating in clinical trials are mostly younger and are often men (Heiat *et al.*, 2002). A critical question is how well these recommendations correspond to the cultural preferences and beliefs of ethnic minorities or immigrants and how well patients adhere to them. According to Leininger, patients who do not receive culture-specific care often show signs of slow recovery and non-adherence to prescribed treatment (Leininger, 1995).

Nurse-led interventions have been shown to decrease the number of admissions, days in hospital, and care costs, as well as to improve physical functioning, adherence to prescribed treatment, self-care strategies, patient satisfaction, quality of life and total survival (Andersen *et al.*, 2005; Sisk *et al.*, 2006; Stewart and Horowitz, 2002; Stromberg *et al.*, 2003). Important aspects of patient-reported quality of care include care-givers' respect for traditional health beliefs and practices, access to professional interpreters and assistance in obtaining social services (Ngo-Metzger *et al.*, 2003). A nurse-based programme for patients with CHF is considered to be more effective than follow ups in primary care in optimising medications and improving self-care behaviours (Mejhert *et al.*, 2004). However, it has been shown that patients with CHF who participated in a nurse-led intervention in primary care retained their physical functioning and emotional well being during one-year of follow-up, while controls significantly deteriorated in physical role functioning and emotional well-being (Mårtensson *et al.*, 2005).

Nursing documents often do not record care planning, specific assessments, nursing interventions and poor adherence to current guidelines (Carlsson *et al.*, 2006; Ehrenberg *et al.*, 2004). Despite efforts by the Swedish health care services and by nursing education programmes to improve nurses' processing and documentation skills, insufficiencies remain in these areas.

Patient-related factors influencing health outcomes

Living with CHF can be restrictive and distressing for both the patients and their families. Difficulties experienced by patients include coping with functional limitation, adapting to living with CHF, side effects of medicines, multiple comorbidities and lack of psychosocial support. For ethnic minorities, problems in coping with the disease may be compounded by communication barriers and cultural differences in illness beliefs and treatment preferences, (Pattenden *et al.*, 2007). Non-adherence to prescribed medications contributes to deterioration of HF symptoms and often to readmissions (Michalsen *et al.*, 1998). However, medication non-adherence is considered to be associated more with the costs of the medications than with ethnicity (Gellad *et al.*, 2007).

Patients who fail to adopt self-management strategies, to participate in the educational sessions and to perform daily weighing have been shown to be at high risk for readmission or mortality (Wright *et al.*, 2003). Factors that influence adherence among patients with CHF include level of knowledge about the condition and recommended regimens, beliefs about these regimens and their benefits, as well as clinical and demographic factors, such as age, gender, education level, marital status, severity of the condition and depressive symptoms (van der Wal *et al.*, 2005). Depression is also associated with higher readmission and mortality rates (Jiang *et al.*, 2001).

In the elderly, who often experience multiple symptoms related to diseases and treatment side effects, the added burden of co-morbid depression and anxiety might increase the perceived severity of the disease. Consequently, the prognostic importance of psychosocial factors, such as level of social support and coping strategies towards the disease, has been stressed (MacMahon and Lip, 2002).

However, information is lacking about immigrants hospitalised for CHF and no studies have investigated whether disparities exist in their treatment, care and frequency or length of hospitalisations compared with native inhabitants. Although several studies have underlined the importance of including minorities, and addressing cultural aspects in HF research (Daly *et al.*, 2002; Gibbs and Lip, 1999; Heiat *et al.*, 2002; Strömberg, 2005), immigrants as a minority group are often excluded from research studies in HF due to communication difficulties.

Most of the published articles on HF/CHF involving ethnic minorities have been carried out in the U.S. Although the U.S. is a culturally and ethnically diverse society comprising many ethnic minorities and immigrants from all over the world,

the findings from those studies may not be applicable to Sweden. One important reason for this concerns the differences in national health care systems between the countries. Furthermore, the bulk of those studies have categorised people into racial or ethnic groups, such as Asian, Asian-Indian, Caucasian, Black, Afro-American, white, non Hispanic whites/blacks, Pacific-Islander and so on (Phinney, 1996). A weakness of such a classification system is that members of the native population and immigrants are not effectively distinguished and may remain hidden within these comprehensive categories. Thus, for example, persons categorised as belonging to an ethnic minority may have lived in the country for generations.

2. SIGNIFICANCE OF THE STUDY

It may be speculated that disparities in the care and treatment of ethnic minorities, due to language barriers, cultural differences or hidden discrimination, that have been reported in other countries may also exist in Sweden. Therefore, the overall aim of this comparative thesis was to describe immigrants with HF in comparison to native Swedes.

In Sweden, the goal of public health, as stipulated by the Swedish National Board of Health and Welfare, is to provide equal and high quality care for the entire population (The National Board of health and Welfare, 2006). Accordingly, all inhabitants of Sweden, including all immigrants, have financially "equal access" to the health care system and pay a maximum annual fee for prescription medications for acute and chronic diseases. Furthermore, immigrants have a legal right to engage interpreters without charge. It is of importance to know whether the goal of providing equal and high quality care for all inhabitants of Sweden has also been achieved for patients with HF from other cultures than the dominant one.

A review of the literature shows that women, the elderly and ethnic minorities are under-represented in clinical trials. It is, however, clearly imperative that these groups be included if trial results are to be generalisable to them as well. Literature searches of major databases, such as Cinahl and Medline, yield few studies that have specifically investigated heart failure and ethnicity, culture, minorities or immigrants. Most previous studies have reported data on minorities (not explicitly immigrants) in countries outside of Sweden and Scandinavia.

A review of the Scandinavian literature on transcultural issues in primary care also reveals that relatively few studies are sufficiently comprehensive to assure the generalisability of the findings (Löfvander and Dyhr, 2002). The main focus in research on HF is often on pathophysiology, clinical or risk factors, epidemiology, readmissions and economical costs. However, little is presently known about immigrants' beliefs, perspectives and experiences of care and treatment.

3. PURPOSE

The overall aim of this descriptive comparative thesis is to describe symptoms, self-care, social support, care and treatment, physical limitation, emotional state and health outcomes, *e.g.* readmissions and mortality, in immigrant compared with native Swedish patients with HF.

The specific aims were to:

I- Describe and compare symptom recognition and health care seeking among immigrants and native Swedes;

II- Describe and compare medical records of immigrant and Swedish patients who had been cared and treated for HF regarding symptoms, diagnosis, treatment, discharge planning and health outcomes, defined as readmissions and mortality;

III- Describe and compare documented care of immigrant and Swedish patients during follow- up visits at a nurse-led heart failure clinic; and

IV- Describe and compare immigrant and native Swedish patients with CHF regarding short-term changes in physical limitations, emotional state, social support and self-care, defined as health care seeking and adherence to medical therapy.

4. DATA

In this thesis, the term immigrant refers to foreign-born individuals residing in Sweden with a native language other than Swedish.

Design and setting

All data in the four studies comprising this thesis were collected at a major university hospital serving a multicultural neighbourhood in Sweden and mainly at the same department of internal medicine. The designs of the four studies are briefly summarized below and outlined in Table 1.

The thesis has a comparative descriptive design. In Study I, semi-structured interviews were conducted to explore symptom recognition and health care strategies related to worsening of CHF. The sole inclusion criterion was admittance for CHF, either acute HF or worsening of HF, at the time of this study. Exclusion criteria were language impairment (not language deficiency) resulting from stroke, dementia etc.; participation in other ongoing studies; permanent institutionalisation; and conditions requiring hospital care other than CHF or critical and severe conditions, such as acute myocardial infarction, acute atrial fibrillation, etc.

Table 1: Research design in the thesis

Paper	I	II	III	IV
Design	Descriptive-comparative	Descriptive-comparative, retrospective	Descriptive-comparative, retrospective	Descriptive-comparative
Data collection	Semi-structured interview guide	Record audit	Record audit	Clinical and demographic data & questionnaires
Methods	Qualitative: Content analysis	Quantitative: Descriptive statistics	Quantitative : Descriptive statistics & Qualitative : Content analysis	Quantitative: Descriptive statistics
Setting	University hospital/ Southern Sweden	University hospital/ Southern Sweden	University hospital/ Southern Sweden	University hospital/ Southern Sweden
Patients	21 immigrant patients and 21 Swedish patients	214 patient records (107 immigrants and 107 Swedes) from 1994-2003	50 patient records (25 immigrants and 25 Swedes) from 1997-2003	23 immigrant patients and 46 Swedish patients
Inclusion criteria	- Diagnosed for HF \leq 6 months - Admitted for CHF or worsening of HF	- Non-Swedish descent - Diagnosed for HF	- Non-Swedish descent - Diagnosed for HF - Referral to the HF clinic at discharge	- Diagnosed for HF \leq 6 months - Admitted for CHF or worsening of HF
Exclusion criteria	- Communication difficulties (<i>e.g.</i> stroke, dementia etc.) - Participation in other ongoing studies - Permanently residing at an institution - Other conditions than CHF needing hospital care - Critical and severe conditions (<i>e.g.</i> , acute myocardial infarction, acute atrial fibrillation, etc.)	None	None	Same as Study I.

Studies II and III have a retrospective and comparative design and describe the care documented in patient records of immigrants who were hospitalised for HF during 1994-2003. These studies relied on the hospital patient registration database from the year 2003 onwards comprising 1054 patients hospitalised for HF.

Inclusion criteria for immigrants were non-Swedish descent (based on name and surname), diagnosed heart failure, and referral to the heart failure clinic at discharge (only Study III). Patients were included consecutively and regardless of age. Swedish patients were also identified by name and surname and otherwise the same inclusion and exclusion criteria were applied. A record audit protocol, based on ESC guidelines (Remme and Swedberg, 2001) for HF diagnosis, treatment and care, was used to collect data from the patient records in both studies.

Study IV has a comparative design describing symptoms, functional and emotional status, self care and social support over time. Inclusion and exclusion criteria were the same as in Study I, described above. Patients were followed during one year, with measurements at inclusion, 4, 8 and 12 months. As the study did not aim to evaluate intervention effects, no attempt was made to match Swedish and immigrant patients. Data comprised results from a battery of questionnaires (Table 2), as well as demographic, clinical, cardiovascular variables and lifestyle risk factors.

Table 2: Questionnaires used in Study III

Data collection	Short description
KCCQ, at baseline and follow ups	Kansas City Cardiomyopathy Questionnaire (KCCQ) developed and validated by Green, Porter, Bresnahan and Spertus (Green <i>et al.</i> , 2000) is a 23-item instrument that measures health-related quality of life in patients with CHF. It measures physical limitation (question 1), symptom frequency, severity and changes over time (questions 2-9), self-efficacy and knowledge (question 11,12), social interference (question 16) and QoL (question 13-15). The instrument has proven to be more responsive to changes in the <i>patient's symptom experiences</i> over time compared to more common QoL instruments (ref).
Short Form 36, at baseline and follow-ups	Short Form-36 (SF-36) is a 36-item general functional status measure. The questionnaire <i>evaluates subjective and various aspects of health status</i> . This multidimensional scale evaluates general health perception (5 items), physical function (10 items) and role limitations (4 items), social function (2 items), mental health (5 items), pain (2 items) and vitality (4 items) as well as two summary indices, Physical Component Summary (PCS) and Mental Component Summary (MCS) (Stewart <i>et al.</i> , 1988).
HAD, at baseline and follow-ups	Hospital Anxiety and Depression Scale (HAD) was developed to <i>detect and measure anxiety and depression</i> . (Zigmond and Snaith, 1983). It is a 14 item self-report questionnaire with anxiety and depression subscales scored with 4 response choices giving scores of 0-3 points for each item. Scores on the 2 subscales range 0-21, 0 indicating no anxiety or depression and 21 maximum levels. Cut off points at 8-10 and > 10 are recommended, indicating possible versus probable anxiety and depression. HAD is a well validated instrument for assessing anxiety and depression in physically ill patients (Bergman <i>et al.</i> , 1991; Herrero <i>et al.</i> , 2003; Lundqvist <i>et al.</i> , 1991; Poole and Morgan, 2006).
MOS SSS at baseline and follow-ups	The MOS Social Support Survey (Sherbourne and Stewart, 1991) was developed within the Medical Outcomes Study to measure various dimensions of <i>perceived social support in patients with chronicle conditions</i> . It is a 19-item instrument which assesses functional support in various dimensions: emotional, informational, tangible, affectionate and positive social interaction. This instrument focuses on perceived availability of social support, if it is needed.
Self-care, at baseline and follow-ups	The Self-care behaviour instrument for patients with CHF was developed and validated by Jaarsma, Strömberg, Mårtensson and Dracup (Jaarsma <i>et al.</i> , 2003) to be used for <i>identifying individual symptom management strategies</i> .

5. METHODS

Ethical approval

In order to access patient records in Studies II and III (record audits), approval was applied for and granted by the department of internal medicine at the research setting. The Regional Ethical Review Board in Göteborg approved studies I and IV and all participants received oral and written information, were assured confidentiality and gave their verbal and written consent.

Procedures

Study I

Qualitative data were obtained from patients with CHF by means of semi-structured interviews conducted between April 2004 and June 2006 at the university hospital. Patients were consecutively recruited from the emergency department, cardiac care units and the HF clinic. Interview protocols comprised the following questions (for some patients through an interpreter): a) Why did you seek care?; b) Which symptoms did you experience?; c) Did you know what kind of illness it was?; d) Do you think you should have sought health care earlier?

Study II

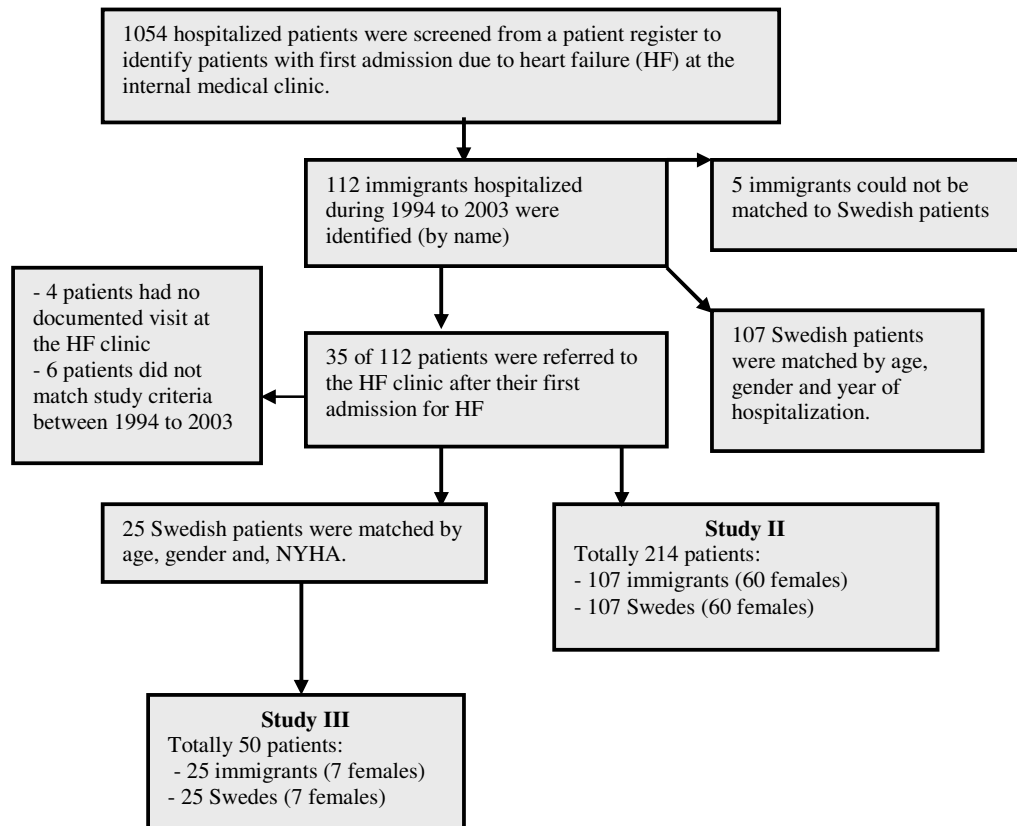
Patient records from 1 054 patients comprising the patient register during 1994-2003 were screened to identify immigrant patients hospitalised for HF for the first time at the medical department. A total of 112 immigrants were able to be identified by name and surname. Non-Swedish descent was later verified by notes in the records which documented country of origin, mother tongue, interpreter need, or interpreter use for the patients. The immigrant group was matched with a Swedish control group regarding age, gender and year of hospitalisation. When matching the groups, differences of up to ± 2 years in age or hospitalization period were accepted. Patient records were audited with regard to ESC recommendations for HF care and treatment (Remme and Swedberg, 2001). Five immigrants could not be matched and were therefore excluded. Thus, patient records of 107 immigrant patients and 107 Swedish patients were reviewed and compared (Figure 1). Nearly equal numbers of patients were readmitted (43 immigrants and 46 Swedes) and a total of 65 readmission records for immigrants and 95 for Swedes were audited.

Demographic data, clinical data, and symptoms were obtained from emergency department admission records; diagnostic investigations were collected from hospital records; and information about treatment and discharge planning were obtained from physicians' discharge reports. Data were gathered and audited for first admission due to HF and for all subsequent readmissions; however, reported results are based solely on record audits of first admission and exclude all readmission data due to insufficient numbers of readmissions for conducting statistical analyses.

Study III

Fifty patient records, from 25 immigrants and 25 Swedes who had been referred to the nurse-directed heart failure clinic for first visit due to CHF (Figure 1), were identified among patient records included in Study II. Patient records were reviewed, also in this study, with regard to adherence to ESC recommendations for non-pharmacological HF management (Remme and Swedberg, 2001).

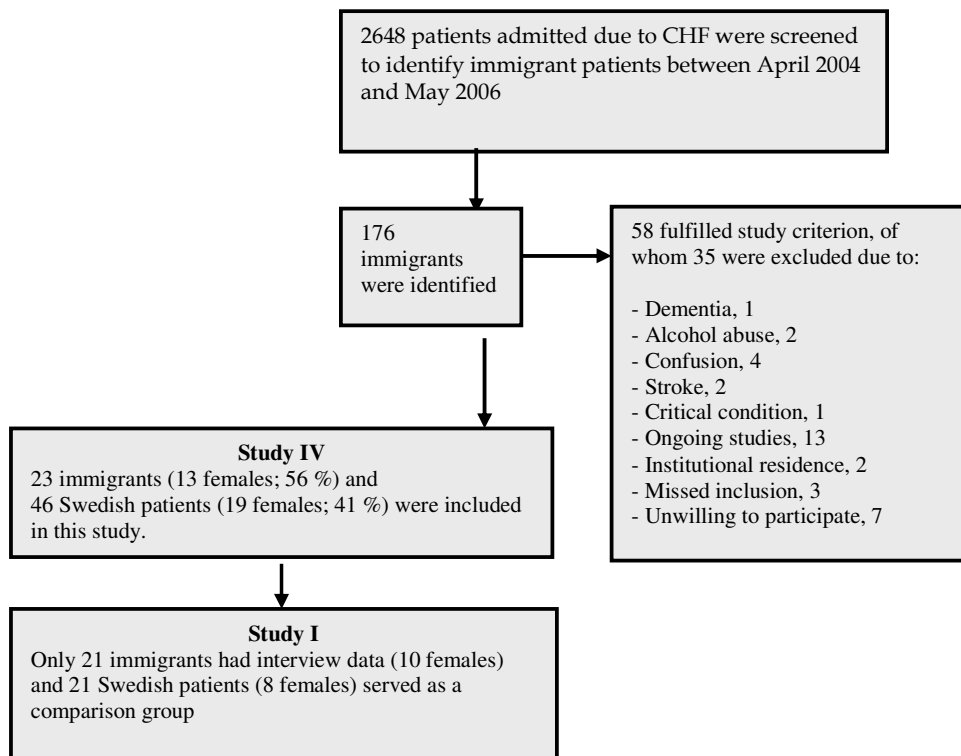
Figure 1: Flow chart Study II- III



Study IV

This study was conducted during April 2004 to June 2006 and the patients were consecutively recruited from the emergency department, cardiac care units and HF clinic. A total of 2 648 patients were screened and of the 176 immigrants who were identified, 58 were eligible for the study and 23 agreed to participate. Forty-eight percent (N=10) were women and 56 % (N=13) of the patients completed the year-long study. Five patients were unwilling to participate and 2 patients were excluded for other reasons. The sample consisted of 23 consecutively recruited immigrants and twice as many Swedes (Figure 2).

Figure 2: Flow chart Study I and IV



Data consisted of responses to interview-administered questionnaires and information regarding demographic (age, sex, country of birth), clinical and cardiovascular variables (*e.g.*, history of heart failure, myocardial infarction, diabetes mellitus, hypertension, antihypertensive medications, NYHA classification, cholesterol) as well as risk factors, such as smoking and alcohol use. Questionnaires used were: Kansas City Cardiomyopathy Questionnaire (KCCQ), Short Form 36 (Stewart *et al.*, 1988), Hospital Anxiety and Depression Scale (HAD), MOS Social Support Survey (Sherbourne and Stewart, 1991), Self-care (Jaarsma *et al.*, 2003). Short descriptions of these questionnaires are provided in Table 2.

Baseline data were collected at the ward during the first two days of hospitalisation. Follow-up data collections were conducted at the research department in the hospital or in the patients' homes if they so wished. Questionnaires were interviewer-administered and interviews were performed using 6 professional interpreters for the 5 languages in the immigrant group. The same interpreter was always used in all interviews with the same patient as a means to increase reliability in the interpretation procedure. No relatives were present during the interviews to prevent possible response bias. Before the first interview at baseline, the researcher and the interpreter reviewed all questionnaire items to minimize misunderstandings during the interview. Patients provided information regarding demographic variables (age, sex, country of origin) and behavioural risk factors. Medical history (*e.g.*, history of heart failure, comorbidities, medications, and EF) was obtained from patient records. Body weight was measured on admission and the New York Heart Association (NYHA) classification was assessed by researchers and assisting research nurses.

Data analysis

Studies I and III

Data were analysed and derived inductively from information contained in the patient records and the interview texts by means of content analysis (Patton, 2002). Each text was first reviewed individually and then all texts were compiled into a single document. This text document was read and re-read in an attempt to gain an overview of the data in order to identify units of analyses. Meaning units relevant to the research question were lifted out and analysed. Meaning units were condensed and categories were formulated. Subsequently, categories of similar content were combined into main categories (Table 3 & 4). To increase the reliability of the analysis the texts were independently analysed by 2 persons and disagreements were discussed to reach consensus about categories and subcategories. In Study I, descriptive statistics were used only to describe participant demographic and clinical characteristics and derived categories were presented as frequencies.

Table 3: Example of content analysis in Study II

Key word	Unit of analysis	Category
Breathing/ circulation	Extremity oedema Bowel oedema	Oedema
	Effort dyspnoea Nightly dyspnoea	Dyspnoea
	Cough	Cough
	Dizziness Dizziness while rising	Dizziness

Table 4: Example of content analysis in Study IV

Unit of analysis	condensation	Category
Difficult to breathe, Breathing was difficult and almost suffocating	Abnormal breathing	Breathing difficulties
I knew that it was the heart, suspected heart infarction	It was the heart	The heart
My wife and my family noticed the worsening, Home care staff recommended that I seek acute care	Not recognise the symptom	Symptom recognition

Studies II and IV

In Study II, descriptive statistics and group comparisons were performed for categorical data using the SPSS statistical package for windows (Pallant, 2005). Data were tested for group differences using chi-square tests and survival analysis was performed using the log-rank method. Statistical significance was set to $P < 0.05$ and data were presented as frequencies and percentages. No readmission data were analysed and only data from the first admission were tested and reported for group differences.

In Study IV, quantitative continuous baseline data were analysed using the non-parametric Mann-Whitney test and baseline category data were analysed using the chi-square test. Between groups differences in change scores from baseline to follow-up for each questionnaire item were analysed using the two-tailed Wilcoxon non-parametric test. Statistical significance was set to $P < 0.05$.

6. RESULTS

Patient characteristics

In Study II, the study sample comprised 107 immigrant patients originating from 27 different countries. Fifty-six percent (N=64) were from Europe and 28% (N=30) were non-European. Mean age was 73 (SD, ±10) years and 60 patients were male. Forty-eight percent lived alone and marital status was not documented for 27 % of patients. Thirty-four percent (N=37) of the patients had a documented left ventricular systolic function measured by ejection fraction. Mean number of coexisting comorbidities was 2 and the most common comorbidities were hypertension 30 % (N=32), diabetes 26 % (N=28) and IHD 47 % (N= 50). On admission, significantly more immigrants had a history of IHD (P= 0.025). Mean and median length of hospital stay was 9 and 7 days, respectively (range 1-29). Twenty-four percent of immigrant patients were readmitted once. First readmission was 2 years after HF diagnosis with a mean follow-up time of 2 years (range 1-10 years). On admission to the emergency department, 16% of the immigrant patients were reported to have used professional interpreters and 52% were accompanied by a relative who acted as interpreter. For the remaining 32%, language proficiency and the use of an interpreter were not reported. During the years 1994 to 2003, 18 immigrants (17 %) and 25 Swedes (23 %) died, which was not a significant difference. Table 5 displays an overview of patients in all studies included in the thesis.

Care and treatment of patients with HF

Diagnostic investigations and medical treatment were similar between the immigrant and Swedish patients. The NYHA functional classification system was not used to evaluate any of the patients either at admission or during hospitalisation. However, it was assessed at discharge in patients referred to the HF clinic, which is mandatory according to referral directives (Study II). Audits of the patient records revealed that provision of HF information was documented for only one immigrant and 3 Swedes at discharge from hospital. The audited patient records also demonstrated inadequacies in documentation regarding psychosocial status, pain, activity status and sleep disturbances (Study II). There was also evidence that interpreters were not sufficiently used at admission, at discharge or at the nurse-led HF clinic.

Several items recommended in the ESC guidelines were not documented in patient records at the nurse-led HF clinic. Examples include information about recognising worsening symptoms, what to do if symptoms occur, advice to family members, and exercise and activities related to work or sexual activity. There were no significant differences found between the patient groups regarding recorded information and education at the nurse-directed HF clinic; however, immigrant patients were less often (12%, N=3; vs. 24%, N=6) provided written HF information (Study III).

Table 5: Patient characteristics in the thesis

Study & Patient groups	I		II		III		IV	
	Immigrant	Swede	Immigrant	Swede	Immigrant	Swede	Immigrant	Swede
Participants (N)	21	21	107	107	25	25	23	46
Age, mean	75	75	73	73	71	71	75	76
Gender (Female)	11	8	47	47	7	7	13	19
Country of origin (N)								
European	18	-	60	-	18	-	18	-
Non-European	3	-	27	-	2	-	5	-
Not documented	-	-	13	-	5	-	-	-
Education (N)								
Compulsory school (< 9 years)	16	16	-	-	-	-	17	32
Upper compulsory school (> 9 years)	1	2	-	-	-	-	1	7
College/University	1	2	-	-	-	-	1	6
EF % (Mean)	35	40	-	-	-	-	35	40
EF <40% (N)	-	-	37	-	17	14	-	-
NYHA- class (N)								
II	5	6	-	-	11	11	5	9
III	16	14	-	-	7	6	17	31
IV	0	0	-	-	0	0	0	5
Most frequent co-morbidities N (%)								
IHD	13 (62%)	14 (67%)	50 (47%)	33 (31%)	13 (52%)	8 (32%)	14 (60%)	32 (70%)
Arrhythmia	13 (62%)	10 (48%)	16 (15%)	25 (23%)	2 (8%)	8 (32%)	13(57%)	27 (59%)
Valvular disease	8 (38%)	7 (33%)	10 (9%)	6 (6%)	3 (12%)	3 (12%)	8 (35%)	10 (22%)
Diabetes	6 (29%)	10 (48%)	28 (26%)	27 (25%)	4 (16%)	1(4%)	6 (26%)	18 (39%)
Hospital stay (day;median/range)	-	-	7 (1-29)	9 (1-31)	-	-	-	-
First readmission (N%)	-	-	25 (23%)	26 (24%)	-	-	-	-
Mortality (N%)	-	-	18 (17%)	25 (23%)	-	-	7 (30%)	5 (11%)

Symptoms, signs and symptom interpretation

A majority of patients at the emergency department were acutely admitted for symptoms and signs. However, twice as many immigrants (n= 10) as Swedes (n= 5) were unaware of which symptoms indicated worsening of CHF (Study I). The two groups did not differ regarding symptoms and signs as indicated in patient records (Study II) and the interview-administrated questionnaires (Study IV) on admission. However, ischemic chest pain was more often (P= 0.004) recorded for immigrants than Swedes at the nurse-led HF clinic (Study III).

Discharge planning and follow-ups

Significantly more immigrants (P= 0.03) were referred to the nurse-led HF clinic for a follow-up visit at discharge (Study II). During the visit significantly fewer clinical parameters (Paper III; Table 5) were assessed in the immigrants and after the follow-up visit fewer immigrants (P= 0.050) were scheduled for another visit (Study III).

Physical limitation, emotional state and social support

Changes over time were similar between the groups regarding social support, physical and emotional state. However, when asked about emotional support, significantly fewer (P= 0.048) immigrants, felt that they had someone to turn to for support (Study IV).

Hospital stay, readmissions, mortality and health care seeking

There were no significant differences regarding length of hospital stay (1-10 days), readmission rates or mortality between the groups (Study II). Regarding self care, immigrants reported significantly higher (P= 0.02) adherence to prescribed medications. However, contacting health care providers in response to typical symptoms and signs of HF were similar over a four month period of time (Study IV). Despite the presence of worsening symptoms at acute admission to the emergency department, both patient groups delayed in seeking care when deteriorations occurred (Study I).

7. DISCUSSION

An overall interpretation of the main findings of this thesis is that immigrants with HF seek acute care mainly due to symptoms and receive largely the same treatment as their native Swedish counterparts. However, several minor dissimilarities were noted. For example, immigrants more often were referred to the nurse-led HF clinics, probably with the aim to provide them with more individualised education and counselling. Moreover, among patients seeking acute care for worsening symptoms of CHF, fewer immigrants than Swedes were able to relate their symptoms to their condition. The poorer ability of the immigrants to recognise signs and symptoms of worsening of CHF may be due to failures to adequately individualize care and to the underuse of professional interpreters.

The impact of these dissimilarities on patient outcomes was not evaluated in this thesis. Nor do we know whether it is even beneficial or appropriate to provide immigrants with the same care and treatment as native Swedes since we did not explore the patients' experiences of received treatment. In the following sections, the main differences between the immigrant and Swedish patient groups will be discussed regarding documentation of care, discharge plans and follow-up, HF information, symptom interpretation, adherence to medications and social support.

Documented patient care

Consistent with previous findings (Ehrenberg *et al.*, 2004), audits of HF clinic patient records showed that biological and medical aspects of care were more often documented than psychosocial aspects. Thus, despite the fact that it is known that non-clinical factors affect readmissions, patient records lacked information regarding such factors as outpatient follow-up, demographic factors (education level, marital status), non-adherence with medications, recommended self-care measures, perceived functional and emotional state.

ESC recommendations for discharge planning include the use of a multi-disciplinary team approach, measures to increase patient recognition of early signs and symptoms, intense repeated education and counselling, inpatient and outpatient follow-up and optimized medical therapy (Swedberg *et al.*, 2005). However, it seems that optimizing medical treatment is the predominant measure taken during hospitalisation and follow-ups. An important goal in the treatment and care of patients with this incurable and chronic condition is to improve quality of life. In this regard, preventative and health promoting interventions, *e.g.*, efforts to meet patient informational needs, should aim to support patients to develop their own self care strategies that are concordant with their own beliefs and preferences.

Several ESC recommendations regarding patient information and education were not documented in the audited records, despite the fact that previous research has underlined the need for patients, regardless of ethnicity and gender, to receive adequate knowledge about CHF and its related treatments (Artinian *et al.*, 2002a;

Lip *et al.*, 2004). Examples of areas that were not documented were advice to family members, exercise and activities related to work and sexual activity, medications to avoid, side effects, how to recognise worsening symptoms, and what to do if symptoms occur. Similarly, patient records contained no information regarding patients' perceptions of treatment regimens, which is consistent with previous research among patients with CHF in home care (Ehrenberg *et al.*, 2004). Ehrenberg and co-workers found that information to patients was noted in only 4 % of the records and that there were also deficiencies in recording specific assessments and interventions, such as regular weighing, etc. Nevertheless, the patients' informational needs may in fact have been assessed and information may have been given, despite the lack of documentation. The failure to document such aspects of care may reflect difficulties in documenting patient's needs, perspectives and preferences. Patients with access to both oral and written information about CHF have been found to express less uncertainty and be more confident about their ability to manage the situation at home (Ekman *et al.*, 2000; Fagermoen and Hamilton, 2006). Therefore, written HF information in major immigrant languages should be provided at HF clinics. Another option is to direct interested patients to patient information provided on the European Society of Cardiology website (www.heartfailurematters.org), at present available in several languages.

Surprisingly, physician summary reports sent to general practitioners (GP) did not document any information given to the patients at discharge about the condition and treatment in either patient group. It was also found that immigrant patient records less often recorded that written information about the condition had been provided at the HF clinic. Hopefully, this shortcoming reflects failures to document rather than to provide patient information regarding self care measures. In this thesis, immigrant and Swedish patient records from only the first follow-up visits at the nurse-led HF clinic were audited and therefore we do not know what effects additional follow-up visits had or how effective oral HF information was in helping patients perform self-care.

At discharge, physicians routinely send a written summary report to the patient's GP and generally do not personally contact the GP for follow-up planning. Discontinuity in patient care, owing to indirect communication between physicians as well as to shortages of GPs and HF clinics in primary care settings, might impact on patients' adherence to prescribed treatment and on their ability to recognise signs and symptoms of deterioration since patients might need support from care providers. There is evidence showing that comprehensive disease management programs for patients with a discharge diagnosis of CHF result in fewer readmissions and improved event-free survival compared to follow ups by physicians (Akosah *et al.*, 2002).

Finding in Study II indicate that a larger proportion of immigrants than Swedes were referred to the HF clinic at discharge could not be explained by differences in numbers of medications needing up-titration or by differences in the severity of the condition as defined by EF or NYHA. A possible explanation is that physicians

may consider immigrants to more likely be in need of more individualised information to compensate for language deficiencies. Hence, education and counselling provided at the HF clinic involve the provision of a substantial amount of information about the condition, medication up titrations and side effects, and self-care measures. Follow-up visits at an inpatient HF clinic have been shown to be more effective in optimising medication doses than follow up visits at primary care (Mejhert *et al.*, 2004). Nurse-led interventions have also been shown to be more effective than routine care in helping patients to retain physical function and emotional state (Mårtensson *et al.*, 2005).

This thesis showed that significantly fewer immigrants than Swedes were scheduled for follow up visits after their first follow-up session. In addition to providing patients with different sources of information, it is recommended that more frequent and individualised educational interventions be undertaken. Such interventions should engage the services of an interpreter to ensure that patients understand and are able to perform recommended self care measures. Previous studies have also reported that ethnic minorities are scheduled for fewer follow-up appointments (Ngo-Metzger *et al.*, 2004; Sarver and Baker, 2000). According to Mårtensson and co-workers, a challenge in the care of patients with worsening CHF is to shorten hospital stay, which augments the importance and need for planning follow-up visits at discharge (Mårtensson *et al.*, 2006).

Interpreter engagement in the health care process

At the emergency department, professional interpreters were engaged for 16 % of the immigrants, whereas 52 % were accompanied by a relative who acted as interpreter. This finding indicates that professional interpreters were clearly underused, which is in line with findings from a review of the Scandinavian literature (Löfvander and Dyhr, 2002). Nonetheless, patients consider culturally and linguistically appropriate health care to be an important aspect of quality of care and prefer professional interpreters to family member interpreters (Ngo-Metzger *et al.*, 2003). It may be speculated that interpreters are underused because it is time consuming for the staff to engage an interpreter. It also involves waiting and inconvenience for the patients. Hence, it is tempting to have a relative accompanying the patient act as interpreter.

However, many patients wait several hours at the emergency department before a clinician becomes available. This time could be used to secure the services of a professional interpreter or to arrange for an interpreting session using available technology, *e.g.*, phone, internet or video conferencing. Routines for booking interpreters for planned hospital visits differ between health care organizations. In some cases, the hospital staff performs the service, whereas in others the patient is expected to do it. Given that interpreters are generally booked in Swedish, it is questionable that patients who already have difficulties in expressing themselves in that language should be given this responsibility.

Professional interpreters were also underused during follow-up visits, which may undermine the physicians' aims to individualise care. Professional interpreters may be better equipped to translate cultural metaphors, used by immigrants to explain symptoms, into Western medical concepts and may help to communicate patient's thoughts and preferences. Failures to use professional interpreters when required may lead to misunderstandings among both caregivers and patients. Such misunderstandings may negatively impact on the patients' understanding of medication, self-care measures, as well as on their ability to interpret and prevent symptoms and signs of worsening of their condition.

Symptom interpretation

As symptom intensity is known to be related to the patient's experience of treatment effects and illness severity (Ekman *et al.*, 2005a; Ekman *et al.*, 2005b), one would expect that symptoms would be assessed and documented at discharge in order to choose treatment strategies and monitor effects of the therapy. However, we found that NYHA functional class was only documented in patients who were referred to the HF clinic (mandatory in the referral form). This confirms previous findings showing low use of this symptom assessment tool in clinical practice (Hobbs *et al.*, 2005). Clinicians do not seem to find the NYHA classification useful and poor agreement has been found between NYHA assessments and patients' own assessments of symptom intensity (Ekman *et al.*, 2007). A useful alternative to the NYHA may be a simple symptom rating scale, for example, a VAS (visual analogue scale) scale or Lickert scale, on which patients can rate their symptoms, and which does not require any particular language skills (Ekman *et al.*, 2005b).

One of the main findings of this thesis is that immigrant patients seeking medical attention for symptoms resulting from deterioration of HF did not relate their symptoms to the condition at readmission to the emergency department. We also found that despite presenting worsening symptoms patients delayed in seeking health care until their symptoms were unbearable. This may suggest that patients lack relevant knowledge about their condition, i.e. how to recognise symptoms of worsening of CHF. Other studies have emphasized that deficiencies in providing information about the condition may lead to poor self-care behaviour, especially concerning adherence to medications and weight monitoring in different ethnic groups (Artinian *et al.*, 2002a; Lip *et al.*, 2004).

Patient-related factors, such as lack of knowledge about how to enter and use the health care system, may also explain delays in seeking health care. Lack of adequate language skills to make physician/nurse appointments at primary care or the need to rely on others to get to the hospital are factors that impede patients from seeking timely care, and that instead encourage them to adopt a "wait and see" strategy, until they can no longer bear their symptoms (Patel *et al.*, 2007).

Adherence to medications

More immigrants than Swedes reported adherence to prescribed medications. This may owe to cultural differences rather than to between-group differences in demographics, such as education level, income, age or gender. Individuals who are brought up in societies based on “dependent collectivism” and hierarchical relationships learn to rely on experts or obey authorities (Oettingen, 1995). Although there are no studies that have investigated adherence among immigrant patients with HF, results from studies of adherence in “racial or ethnic” groups are conflicting (Artinian et al., 2002b); (Tijerina, 2006). However, findings suggesting poorer adherence among these groups may be explained by financially unequal access to health care. In Sweden, the social welfare and health care systems reduce the risk for poverty and unequal access to health care and may thereby contribute to adherence to medications and health care seeking. According to Tijerina, greater non-adherence among Mexican-Americans owes to factors such as poverty, immigrant status, perceived loss of identity and family dysfunction (Tijerina, 2006).

However, adherence data is often based on self report and it has been suggested that the reliability of such data may be limited by the fact that patients with HF sometimes may forget to follow prescriptions or make their own adjustments of dosages and intervals (van der Wal *et al.*, 2006). It is also known that 5-10% of patients with HF are completely non-adherent, 50-60% are always adherent and the remaining patients are partly adherent (Sabate, 2004).

Social support

Perceived social support was significantly lower among immigrants than Swedes. Poor social support among ethnic minorities has also been reported by Pattenden and co-workers (Pattenden *et al.*, 2007). Swedes have a wider circle of acquaintances to socialize with, such as colleagues, neighbours, friends, family and other relatives. In contrast, many immigrants, especially the elderly, may have only a handful of acquaintances outside their own language/ethnic group. The Social Support Survey, used in this thesis, assesses the quantity rather than the quality of perceived support. Thus, although immigrants have access to less social support in terms of numbers of people to turn to, the quality of that support may be as good as that of their Swedish counterparts.

Methodological aspects

Strengths of the thesis

A strength of this thesis is that it focuses on a chronically ill patient group that has been virtually ignored in both Swedish and international research, namely immigrants with CHF.

Study design and data source

The use of a retrospective study design and secondary data (patient records) may be considered a limitation of the thesis. On the other hand, patient records are not as prone to bias as are other types of data because they are not primarily produced for research purposes. Data derived from retrospective study designs and record audits may also be considered to be of questionable validity. However, patient records are an invaluable source of information about not only the provided care but also about what aspects of care that caregivers judge to be important enough to document. Patient records, viewed as systematic documentation of patient care and treatment, should be considered valid sources of data, which, despite their limitations, *e.g.*, not reflecting patient perspectives, may be especially valuable for following trends over time.

Inclusion criteria

The practice of identifying the ethnic background of patients by means of surname and name may be questioned; however, since no systematic register of patients' nationality exists in the Swedish health care system, our only recourse was to identify immigrant inhabitants by this method – and crosschecking with patient records for notes on nationality, ability to speak Swedish or interpreter need. Naturally, the reliability of our data would be better if we had had direct access to patient's self-reported origin; however, there is evidence that surnames and self report are equally viable methods for identifying ethnic origins because surnames are passed on from generation to generation (Quan *et al.*, 2006b). For geographical and historical reasons, Scandinavian names are very similar and it may therefore be difficult to distinguish Swedish names from those of other Scandinavian countries.

Furthermore, Swedes are neither culturally nor ethnically homogenous and therefore to identify Swedes by name and surname is also problematic. For example, some ethnic groups may have changed their surnames to typical Swedish ones in order to facilitate assimilation. Study II included patients with heart failure both as a primary and secondary diagnosis. This may be perceived as a weakness of the study; however, subgroup analyses between diagnosis groups did not show any notable differences in diagnosis at discharge or in the management of heart failure.

Matching criteria

The NYHA classification system was used to match the immigrant and native Swedish patient groups in Study III. Ejection fraction (EF) was not used. Nevertheless, EF, which is considered to be an objective indicator of reduced LV systolic function, did not significantly differ between the groups. In Study IV, no criteria were used to match the patient groups because it was not an interventional study. Despite this, we found no significant between-group differences in patient characteristics or clinical variables, *e.g.*, gender, age, education level, marital status, income or EF, that could affect study findings.

Cultural aspects of standard health questionnaires

The use of interpreters may be perceived to negatively affect the reliability of our data. We engaged, as far as possible, certified interpreters from the same interpreter agency, and the same interpreter was always used for the same patient and language group at all interview occasions. All questionnaires were introduced to the interpreters prior to the first interview. In order to evaluating the method interpreters were asked about difficulties in the interpretation process. Consistent with results from two previous studies (Fatahi *et al.*, 2005; Hudelson, 2005), most of our interpreters reported that some words or expressions, such as cultural metaphors, were not possible to translate into a single word or phrase, but rather required somewhat lengthy explanations. The authors of the above studies point out that difficulties in translating culturally specific expressions are potential sources of misunderstandings when translating medical terms. Therefore, they recommend using professional medical interpreters in order to more effectively bridge communication between caregivers and immigrants – a recommendation that health care providers might find difficult to recognise.

It may be speculated that cultural differences exist between countries due to historical, political, socio-structural and religious reasons. The questionnaires used in this thesis were designed and developed in Western countries and reflect the cultural metaphors, living standards and ideals of those countries. Consequently, the questionnaires may not be suitable for people who are not brought up in the western world. Some attitudes expressed in the HAD and the Social Support Survey represent social and cultural ideals, *e.g.* what is relaxing, what makes one feel good/bad, ways of showing affection and devotion to one another, and recreational or spare time activities. Therefore, we do not know how valid such standardized health questionnaires are in assessing emotional status and perceived social support in patients outside of Western and Northern Europe. Previous research findings have also questioned the universality of such measures and recommended further research to resolve probable inadequacies in used concepts and measures (Stewart and Napoles-Springer, 2000; Stewart and Napoles-Springer, 2003).

Generalisability of the findings

Immigrants in Sweden, and elsewhere, are a heterogeneous population with regard to national origin, socioeconomic status, language, religion, etc. Therefore, our findings may not be generalizable beyond the patients included in these studies. Further qualitative and quantitative research is needed among immigrants, both across national groups and cultural/ethnic heterogeneous subgroups in order to collect more specific data on variables related to ethnicity, culture and patient-related factors relevant to patient outcomes. These factors could be of a demographic or psychosocial character. Among patient-related factors are literacy, acculturation level, socioeconomic status, spirituality, diet and lifestyle habits. Furthermore, perceived severity of disease, symptom experience and level of

symptom distress, response to the illness, coping strategies, self-care practices, and process of decision making about care plans and treatment choices are also important to consider.

Finally, the small sample size and the fact that the studies were all conducted at the same setting also restrict the generalisability of some of the findings.

8. CONCLUSION

Although immigrant and Swedish patients with CHF were provided largely the same care and treatment, fewer immigrants were able to relate their symptoms to their condition when seeking acute care. Immigrants also reported higher adherence to prescribed medication and were more often referred to the nurse-led HF clinic by physicians at discharge from hospital, possibly with the expectation that the patients would receive more individualised care and follow up. Information about how and if patient education and counselling had been carried out was rarely documented in the patient records.

9. IMPLICATIONS

Practice

- Documentation of patient care should be further improved and should include the patients' own perceptions and descriptions of their problems in their own words, without translating them into medical terms. It should also register all performed assessments and interventions, which may improve communication between caregivers in different health care settings and consequently improve the efficiency of future care plans.
- Serious efforts should be made by health professionals to maintain continuity of care through structured discharge planning (including nursing discharge plans).
- This thesis showed that the care and treatment of immigrant and Swedes were fairly similar. However, health professionals should be aware that equality and equity of care and treatment are not synonymous. Equity implies that management strategies need not be the same for all patients but rather should fit the needs of the individual patient.
- Wider use of professional interpreters may help to improve communication between care providers and immigrants, and thereby potentially improve health outcomes for immigrant patients. In this regard, more resources should also be set aside to recruit interpreters, as well as ward and hospital staff with immigrant backgrounds.

Research

- To examine the impact of CHF and its treatment among non-European immigrants, including a wider array of variables, such as cultural, social and emotional factors influencing the condition, symptom interpretation and experience.
- To explore predictors of non-intentional or intentional delays in seeking health care, as well as barriers and facilitators to seeking timely care among immigrants. In this regard, patient characteristics such as the patients' world views, causal explanations of the disease, meaning of illness and disease should be considered.
- To prospectively explore the impact of nurse-led HF clinics on patient outcomes, *e.g.*, readmissions, mortality and quality of life among immigrants.
- To evaluate interpreter use in relation to knowledge, physical function and wellbeing, self care and patient satisfaction.
- To develop more culturally sensitive measures and validate the cross-cultural applicability of standard health questionnaires, such as the HAD and social support questionnaires, among non-western populations.

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