

# CLINICAL ENCOUNTERS WITH DIFFERENT ILLNESS REALITIES

Qualitative studies of illness meaning and restructuring of illness meaning among  
two cultural groups of female patients in a multicultural area of Stockholm

SOFIE BÄÄRNHIELM



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**Stockholm, 2003**

## A B S T R A C T

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**Background:** Mental health care in Sweden encounters a multicultural population. Meaning given to illness may differ between patient, family and caregiver and this affects the clinical encounter and outcome of treatment.

**The general aim** of this thesis is to explore, understand, and describe how a group of Swedish and a group of Turkish-born women, assessed as somatizing by their caregivers, and in contact with local health care in Western Stockholm, gave meaning to their illness. **Additional aims** are to explore participants' restructuring of illness meaning, caregivers' experiences and meanings of encountering patients using a bodily idiom for emotional distress, in a multicultural milieu, and how caregivers imparted their professional agenda of illness meaning.

**Methods and results:** The thesis consists of five explorative qualitative studies and one paper discussing methodology. Data were collected 1997-2001. *Study I* explores structures of illness meaning among 8 Swedish-born women. Data were collected via 25 interviews. Some data were collected to reflect the caregivers' professional opinions. *Study II* explores structures of illness meaning among 10 Turkish-born women. Data were collected via 29 interviews. Some data were collected to reflect the caregivers' professional opinions. *Results of Studies I and II* describe illness expressions, healing strategies, meanings, and initial differences in illness meaning between participants and caregivers, caregivers' introduction of a "psychological language" of distress, and participants' efforts to grasp their caregivers' meaning. *Study III* explores restructuring of illness meaning among the 10 Turkish-born women from Study II. Data were collected by a secondary analysis of data from Study II and 8 new interviews. *Results* describe restructuring to include loss of meanings, shifts in expressions and healing strategies, and a push towards restructuring illness into a psychological or psychiatric framework. Restructuring was in many ways a disruptive experience and participants tried to bridge gaps between perspectives. In this, they perceived poor support from their social context. *Study IV* explores restructuring of illness meaning among the 8 Swedish-born women from Study I. Data were collected by a secondary analysis of data from Study I and 7 new interviews. *Results* describe restructuring to include two trends, firstly an acceptance of a psychological language of distress and secondly paying attention to stress and demanding work conditions. Restructuring was not uncomplicated and participants tried to bridge gaps between perspectives. In this, the social context was important. *Study V* explores caregivers' experiences and meanings of encountering patients using a bodily idiom for emotional distress in a multicultural milieu and how caregivers imparted their professional agenda of illness meaning. Data were collected via 7 focus group interviews. *Results* describe caregivers' experiences and meanings and that, in imparting their professional agenda, caregivers lacked support from organisational structures and clinical models for adapting work to the multicultural population and for treating mental ill health in primary care. *Paper VI* highlights the experiences, and reviews the literature, of using focus groups as a qualitative method in transcultural psychiatric research.

**Discussion and conclusion:** From the results of Studies III & IV, I suggest that Antonovsky's Sense of Coherence Concept may be relevant when considering the restructuring of illness meaning, and that constructing coherence between experience, expression, and past and new illness meanings, may be significant for patients' recovery. From the results of Studies I-V, from a patients perspective, I wish to formulate the following hypotheses for the clinical encounter of emotional distress and mental illness in multicultural milieus: 1) Constructing a sense of coherence between experience, expression, past and new meanings given to illness, may be significant for patients' recovery. 2) Regarding clinical transaction of meanings, for the disruptive experience of illness, restructuring patients' illness meaning needs to be carried out in such a way as to facilitate for the patient to construct a sense of coherence between her/his illness meaning and the caregivers' medical framework. 3) The individual illness reality of the patient needs to be given an integral and important role as a collaborative resource alongside the medical framework.

**Implications:** For the clinical encounter, results stress the significance of becoming acquainted with patients' meanings associated with illness experiences. For caregivers, in multicultural milieus, results argue for the importance of support from organisational structures and shared formulated models for adapting their work to the diversity of the population and for treating mental ill health in primary health care. For research, results point to the significance of further studies on interaction between health care and individuals and different social/cultural groups as well as on how people make sense of, use, and cope with the clinical encounter for recovery. This is of special importance for patients in an immigration situation as immigration involves being uprooted, dislocated and relocated.

**Key words:** transcultural psychiatry, somatization, illness meaning, immigration, sense of coherence

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**Sofie Bäärnhielm**

leg. läkare, med.lic.



## A K A D E M I S K   A V H A N D L I N G

som för avläggande av medicine doktorsexamen vid Karolinska Institutet  
offentligen försvaras på engelska språket i hörsalen Novum, Huddinge Sjukhus

Fredagen den 10 oktober 2003, klockan 09.00

**Handledare**

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KAROLINSKA INSTITUTET • STOCKHOLM 2003

The person on the front cover has no connection with the contents of this thesis.

Dissertation for the degree Doctor of Medical Science presented at Karolinska Institutet 2003.

Bäärnhielm, S (2002). Clinical encounters with different illness realities. Qualitative studies of illness meaning and restructuring of illness meaning among two cultural groups of female patients in a multicultural area of Stockholm. Division of Psychiatry, Neurotec Department, Karolinska Institutet, Stockholm, Sweden. ISBN: 91-7349-641-3

Till  
***Nanna, Erik och Olof***

Ett bidrag till att utveckla vården för en mångkulturell befolkning.  
(To Nanna, Erik, and Olof, a contribution to improve care for a multicultural population.)

*“In order truly to help someone else, I must understand more than he – but certainly first and foremost understand what he understands. If I do not do that, then my greater understanding does not help him at all. If I nevertheless want to assert my greater understanding, then it is because I am vain or proud, then basically instead of benefiting him I really want to be admired by him. But all true helping begins with a humbling. The helper must first humble himself under the person he wants to help and thereby understand that to help is not to dominate but to serve, that to help is not to be the most dominating but the most patient, that to help is a willingness for the time being to put up with being in the wrong and not understanding what the other understands”*

Kierkegaard<sup>1</sup> (1998, p. 45)

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<sup>1</sup> Søren Kierkegaard, Danish philosopher 1813- 1855.



## ABSTRACT

**Background:** Mental health care in Sweden encounters a multicultural population. Meaning given to illness may differ between patient, family and caregiver and this affects the clinical encounter and outcome of treatment.

**The general aim** of this thesis is to explore, understand, and describe how a group of Swedish and a group of Turkish-born women, assessed as somatizing by their caregivers, and in contact with local health care in Western Stockholm, gave meaning to their illness. Additional aims are to explore participants' restructuring of illness meaning, caregivers' experiences and meanings of encountering patients using a bodily idiom for emotional distress, in a multicultural milieu, and how caregivers imparted their professional agenda of illness meaning.

**Methods and results:** The thesis consists of five explorative qualitative studies and one paper discussing methodology. Data were collected 1997-2001. Study I explores structures of illness meaning among 8 Swedish-born women. Data were collected via 25 interviews. Some data were collected to reflect the caregivers' professional opinions. Study II explores structures of illness meaning among 10 Turkish-born women. Data were collected via 29 interviews. Some data were collected to reflect the caregivers' professional opinions. Results of Studies I and II describe illness expressions, healing strategies, meanings, and initial differences in illness meaning between participants and caregivers, caregivers' introduction of a "psychological language" of distress, and participants' efforts to grasp their caregivers' meaning. Study III explores restructuring of illness meaning among the 10 Turkish-born women from Study II. Data were collected by a secondary analysis of data from Study II and 8 new interviews. Results describe restructuring to include loss of meanings, shifts in expressions and healing strategies, and a push towards restructuring illness into a psychological or psychiatric framework. Restructuring was in many ways a disruptive experience and participants tried to bridge gaps between perspectives. In this, they perceived poor support from their social context. Study IV explores restructuring of illness meaning among the 8 Swedish-born women from Study I. Data were collected by a secondary analysis of data from Study I and 7 new interviews. Results describe restructuring to include two trends, firstly an acceptance of a psychological language of distress and secondly paying attention to stress and demanding work conditions. Restructuring was not uncomplicated and participants tried to bridge gaps between perspectives. In this, the social context was important. Study V explores caregivers' experiences and meanings of encountering patients using a bodily idiom for emotional distress in a multicultural milieu and how caregivers imparted their professional agenda of illness meaning. Data were collected via 7 focus group interviews. Results describe caregivers' experiences and meanings and that, in imparting their professional agenda, caregivers lacked support from organisational structures and clinical models for adapting work to the multicultural population and for treating mental ill health in primary care.

*Paper VI* highlights the experiences, and reviews the literature, of using focus groups as a qualitative method in transcultural psychiatric research.

**Discussion and conclusion:** From the results of Studies III & IV, I suggest that Antonovsky's Sense of Coherence Concept may be relevant when considering the restructuring of illness meaning, and that constructing coherence between experience, expression, and past and new illness meanings, may be significant for patients' recovery. From the results of Studies I-V, from a patients perspective, I wish to formulate the following hypotheses for the clinical encounter of emotional distress and mental illness in multicultural milieus: 1) Constructing a sense of coherence between experience, expression, past and new meanings given to illness, may be significant for patients' recovery. 2) Regarding clinical transaction of meanings, for the disruptive experience of illness, restructuring patients' illness meaning needs to be carried out in such a way as to facilitate for the patient to construct a sense of coherence between her/his illness meaning and the caregivers' medical framework. 3) The individual illness reality of the patient needs to be given an integral and important role as a collaborative resource alongside the medical framework.

**Implications:** For the clinical encounter, results stress the significance of becoming acquainted with patients' meanings associated with illness experiences. For caregivers, in multicultural milieus, results argue for the importance of support from organisational structures and shared formulated models for adapting their work to the diversity of the population and for treating mental ill health in primary health care. For research, results point to the significance of further studies on interaction between health care and individuals and different social/cultural groups as well as on how people make sense of, use, and cope with the clinical encounter for recovery. This is of special importance for patients in an immigration situation as immigration involves being uprooted, dislocated and relocated.

**Key words:** transcultural psychiatry, somatization, illness meaning, immigration, sense of coherence

## LIST OF PUBLICATIONS

This thesis is based on the following papers, which are referred to by their Roman numerals. Papers I - V present results from five explorative studies. Paper VI addresses methodological issues. Papers I and II have been included in the licentiate thesis entitled "Clinical encounters with different illness realities" (Bäärnhielm, 2000) at the Karolinska Institutet.

- I** Bäärnhielm, S. (2000). Making sense of suffering. Illness meaning among somatizing Swedish women in contact with local health care services. *Nordic Journal of Psychiatry*, 54(6), 423 - 430.
  
- II** Bäärnhielm, S., & Ekblad, S. (2000). Turkish Migrant Women Encountering Health Care in Stockholm. A qualitative Study of Somatization and Illness Meaning. *Culture, Medicine and Psychiatry*, 24(4), 431- 452.
  
- III** Bäärnhielm, S. (accepted). Restructuring Illness Meaning Through the Clinical Encounter: A process of Disruption and Coherence. *Culture, Medicine and Psychiatry*.
  
- IV** Bäärnhielm, S. (submitted). Making sense of different illness realities. Restructuring of illness meaning among Swedish-born women.
  
- V** Bäärnhielm, S., & Ekblad, S. (manuscript). In unfamiliar territory: caregivers' encounters with somatic communication of mental ill health in a multicultural community.
  
- VI** Ekblad, S., & Bäärnhielm, S. (2002). Focus Group Interview Research in Transcultural Psychiatry - Reflections on Research Experiences. *Transcultural Psychiatry*, 39(4), 484-500.

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## ABBREVIATIONS

DSM – IV	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, American Psychiatric Association
IPM	National Institute for Psychosocial Factors and Health, Stockholm
PTSD	Post-traumatic Stress Disorder
QSR NUD*IST ver 4 (N4)	Non numerical Unstructured Data Indexing Searching and Theory-building
QSR Nvivo 1.2 (Nvivo)	QSR NUD*IST Vivo Software program, developed from N4
SCID - RV - I	Structured Clinical Interview for DSM IV-Axis I Disorders. Research Version
SOC	Sense of Coherence

## CONTENTS

<b>PROLOGUE</b> .....	1
<b>SAMMANFATTNING PÅ SVENSKA (SUMMARY IN SWEDISH)</b> .....	4
<b>TÜRKÇE ÖZET (SUMMARY IN TURKISH)</b> .....	10
<b>BACKGROUND</b> .....	17
<b>Introduction</b> .....	17
<b>Clinical experiences</b> .....	20
<b>Clinical context and Turkish immigration to Sweden</b> .....	21
<b>Immigration, health and mental ill health in Sweden</b> .....	23
<i>Acculturation and the role of the immigration context in health</i> .....	24
<i>Immigrants and musculoskeletal pain conditions</i> .....	25
<i>Women immigration and health</i> .....	26
<b>Immigration and mental health care utilisation</b> .....	27
<b>THEORETICAL FRAMEWORK</b> .....	29
<b>Culture and formulation of emotional distress</b> .....	29
<i>The concept of culture</i> .....	30
<i>Culture and idioms of distress</i> .....	30
<b>Using a bodily idiom for emotional distress</b> .....	32
<i>Historical reflections on body mind dualism</i> .....	33
<i>Somatization versus psychologization</i> .....	34
<i>Decoding meanings of somatic symptoms</i> .....	36
<b>Explanatory models, illness meaning and clinical transaction of meanings</b> .....	37
<i>Illness meaning and clinical transaction of meanings</i> .....	38
<b>The sense of coherence concept</b> .....	39
<b>AIMS OF THE STUDIES</b> .....	41
<b>METHODS</b> .....	43
<b>Methodological framework of the studies</b> .....	43
<i>Design and research question</i> .....	45
<i>Collecting data via interviews</i> .....	45
<i>Sampling</i> .....	46
<i>Data analysis and grounded theory</i> .....	47
<i>Analysing data from focus groups</i> .....	48
<i>Transcription</i> .....	49
<b>Validity in qualitative research</b> .....	49
<i>Putting a name to quality</i> .....	50
<b>Ethics</b> .....	52
<b>Procedure</b> .....	53
<i>Sampling and samples</i> .....	53
<u>Study I. sampling and sample</u> .....	53

<u>Study II, sampling and sample</u> .....	54
<u>Study III, sampling and sample</u> .....	56
<u>Study IV, sampling and sample</u> .....	56
<u>Study V, sampling and sample</u> .....	56
<i>Data collection</i> .....	57
<u>Studies I and II, data collection</u> .....	57
<u>Studies III and IV, data collection</u> .....	60
<u>Study V, data collection</u> .....	61
<i>Research question and data analysis</i> .....	62
<u>Studies I and II, research question and data analysis</u> .....	62
<u>Studies III and IV, research question and data analysis</u> .....	65
<u>Study V, research question and data analysis</u> .....	66
<i>Validity</i> .....	67
<u>Studies I–IV, validity</u> .....	67
<u>Study V, validity</u> .....	69
<u>Presenting the studies</u> .....	69
<b>RESULTS</b> .....	71
<b>Studies I and II, results</b> .....	71
<i>Historical reflections</i> .....	73
<b>Studies III and IV, results</b> .....	77
<b>Study V, results</b> .....	78
<b>DISCUSSION</b> .....	80
<b>On theoretical framework</b> .....	80
<i>Somatization</i> .....	80
<i>Explanatory models</i> .....	81
<b>On methodology</b> .....	82
<i>Choice of methods</i> .....	82
<i>Limits and strengths</i> .....	83
<b>On results</b> .....	86
<i>Comparative comments</i> .....	86
<u>Studies I and II, comparative comments</u> .....	86
<u>Studies III and IV, comparative comments</u> .....	87
<i>Sense of coherence and restructuring illness meaning</i> .....	89
<i>Caregivers' contextual situation</i> .....	89
<b>CONCLUDING REMARKS WITH IMPLICATIONS FOR PRACTICE AND FUTURE RESEARCH</b> .....	91
<b>Implications for clinical practice</b> .....	92
<b>Implications for future research</b> .....	93
<b>ACKNOWLEDGEMENTS</b> .....	94
<b>EPILOGUE</b> .....	96

<b>REFERENCES</b> .....	97
<b>APPENDIX</b> .....	105
<b>Appendix 1 - interview guide for Studies I and II</b> .....	105
<b>Appendix 2 - interview guide for Studies III and IV</b> .....	109
<b>PAPERS I – VI</b>	



## PROLOGUE

I did not embark upon this work with the intention and ambition of writing a doctoral thesis. The process started with unanswered questions raised in my clinical work with many refugees and other immigrants at a psychiatric outpatient clinic in a multicultural area in Stockholm. My research has been fuelled by curiosity but also by involvement, emotions of being upset and reflections over a situation of inadequate health care delivery for exposed groups of patients. My curiosity and emotions came to be canalised into a research process through my contact with Associate Professor Solvig Ekblad at IPM and the Karolinska Institutet. Solvig has been my supervisor for this thesis and has given unstinting methodological support and encouragement during the whole research process. Questions arising from my clinical work initiated the first two studies. The subsequent three studies originated from questions emerging from the results of the two first studies. To follow the path of unanswered questions, to give time to reflect on unclear methodological issues, and finally, to summarise findings after twenty years of clinical work as a physician has felt like a challenging privilege.

The original questions addressed in these studies, of exploring patients' illness meaning, evolved from my experiences of working eight years (1990-1998) as a psychiatrist at Spånga psychiatric outpatient clinic. I encountered patients from the socio-economically deprived suburbs of Rinkeby and Tensta in Western Stockholm on a daily basis. These suburbs have become symbols of Sweden as a country of cultural diversity, disparity, multi-ethnicity and social complexity. This is in contrast to the 60s when I grew up with the social dream of building "Folkhemmet", (literal translation: people's home<sup>1</sup>), the ideal of the good family home according to society and the state. For me it was a dream and an illusion, where cultural complexity and disparity or injustice belonged to other parts of the globe.

The suburb of Rinkeby is popularly known as "the village of the world", as the great majority of the inhabitants were born outside Sweden. The names of the suburbs, Tensta and Rinkeby, originate from Iron Age settlements. The encounter with patients from different parts of the world presented me with difficulties and challenges regarding my

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<sup>1</sup> The English word used by Lewis (1992, p. 168) for the concept "Folkhemmet" is "People's home". The meaning of the concept is formulated as: "The most powerful image in Swedish social democracy has been that of building the 'people's home', which encompasses the double idea first, of society and state as a good family home, where no one is privileged, all co-operate and no one tries to gain advantages at another's expense; and second of ensuring that productive capacity is used to the advantage of people and their families."

basic task as a physician, i.e. that of helping patients cope with their suffering. I found that the models of understanding suffering and expressions of emotional distress and treatment that I had learned during my medical training and residency in psychiatry did not fit with the reality that I encountered. My professional and lay knowledge was not good enough to make sense of my experiences, either for improving the quality of the work, or for being an advocate for change. I was reminded of my childhood when I realised that the historical and socially patterned cultural model for understanding and interpreting the world, the model I grew up with, was not sufficient for understanding the world outside.

As time has passed, I have come to see and appreciate the richness of the stories that enabled me to enter invisible worlds that I grew up with in my family of origin. I think that these studies, in starting out with searching for patients' meaning behind the confines of the everyday clinical context, are a result of the interaction of an increasingly perceived need for new understanding and development of the clinical work, and my private personal history. The possibility of becoming acquainted with other people's illness narratives as a part of a research methodology offered me an opportunity of combining professional and personal interests. This has been important for performing the time-consuming work of qualitative research.

Thinking about the clinical work that initiated this thesis, a multitude of patients and narratives comes to mind. I would like to describe the patients and their suffering in a form and framework other than that of a medical record. To give the reader a clue as to why this research came to take the direction that it has, I would like to begin by referring to one of the many clinical encounters that has made a lasting impression on my thinking and work.

I had just started to work as a consultant psychiatrist. The social insurance office referred a man for assessment and required a psychiatric diagnosis, assessment of working capacity as well as a recommendation regarding appropriate rehabilitation measures. The patient was an Assyrian man from Turkey. He suffered from pain in the left half of his body. The right half was healthy. The pain had started eighteen years ago when he migrated. He reported years of suffering, demanding social conditions and involuntary migration, and said his life no longer had any value. On the advice of an elderly woman he had tried to be cured using a buttercup. Initially he felt better but after a while experienced

that the treatment had burned his muscles. I asked myself, how could I understand his symptoms, what diagnosis should I make, what symbolic message was there, how could we collaborate and what was I to write in the report to the insurance office? I could not find adequate answers and I remember the strange feeling of sharing the same room, time, place and words with the man, but in some way not the same reality. I made a psychiatric assessment with which I was not satisfied. This patient, one of the first that I met as a qualified psychiatrist, was a man who fuelled my thoughts and gave rise to many unanswered questions. During my further clinical work, I encountered patients that presented suffering in a similar way. Most of them were women, which is why this research has focused on women and their understanding of their current illness and suffering.

The findings of the studies are based on interpretations of interviews (a total of 69) of eighteen women conducted at three different points of time over a five year period (1997 – 2001) and on seven focus group interviews with 35 caregivers. Would the findings have been different with other patients, caregivers and local contexts? In pondering this question about the relevance of some individual experiences I would like to refer to the prologue from V.S Naipaul's book *Beyond Belief* (1998, p. 2). Naipaul makes an excursion among converted people based on individual stories. Asking himself if the stories would be different with other narrators Naipaul writes; "...the train has many coaches, and different classes, but it passes through the same landscape."

I want to add that this thesis is based on my interpretations of others' expressions of their inner worlds. The interpretations have been made with the rigour of research methodology. However, in the last analysis, the interpretations are my attempt to try to understand and describe the other.

## **SAMMANFATTNING PÅ SVENSKA**

### **(SUMMARY IN SWEDISH)**

#### **Bakgrund**

Den psykiatriska vården i Sverige möter en allt mer mångkulturell befolkning. Kulturella faktorer kan påverka symptom och förlopp av psykisk sjukdom. Patienters förklaringar till upplevd sjukdom (explanatory model) påverkas av historiska, och sociala förhållanden och kan skilja sig från vårdgivares medicinska modell. Skillnader i förklaring av sjukdom kan leda till olika förväntningar, kommunikationssvårigheter och till bristande vård (Kleinman, 1978).

Bakgrunden till dessa studier är min kliniska erfarenhet från psykiatriskt öppenvårdsarbete i ett mångkulturellt område i västra Stockholm, att patienter ofta hade för mig främmande sjukdomsförklaringar och att detta kunde påverka förståelse, behandling och sjukdomsförlopp.

#### **Övergripande syfte**

Det övergripande syftet med avhandlingen är att utforska, förstå och beskriva hur en grupp av svenskfödda och en grupp av turkiskfödda kvinnor skapade mening av sin upplevda sjukdom. Deltagarna var i kontakt med sjukvården i västra Stockholm och var av sina vårdgivare bedömda att somatisera psykisk ohälsa. Somatisera har definierats som en tendens att uppleva och kommunicera psykisk ohälsa och sociala problem med kroppsliga symtom och söka medicinsk hjälp därför (Lipowski, 1987). Ytterligare syften är att utforska förändring av patienternas meningsskapande, samt att utforska vårdgivares erfarenheter av att möta patienter som uttrycker psykisk ohälsa med kroppsliga symtom och vårdgivares erfarenhet av att introducera sin sjukdomsförklaring.

Avhandlingen består av fem delstudier och en metodartikel. Resultaten av studierna bygger på tolkningar av intervjuer med 18 kvinnor, gjorda vid tre tillfällen under fem år (1997-2001). Sammanlagt gjordes 69 individuella intervjuer med kvinnliga patienter och sju fokusgruppsintervjuer med 35 vårdgivare. De turkiskfödda kvinnorna hade den gemensamma erfarenheten av att ha immigrerat och de hade samtliga en låg socioekonomisk status. De svenskfödda kvinnorna hade en blandad socioekonomisk status. De två första delstudierna (I and II) har ingått i min licentiat avhandling vid Karolinska Institutet (Bäärnhielm, 2000).

### **Studie I:**

Making sense of suffering. Illness meaning among somatizing Swedish women in contact with local health care services. Publicerad i *Nordic Journal of Psychiatry*, 54(6), 423 – 430, 2000.

#### *Syfte och metod*

Studien syftar till att utforska hur åtta svenskfödda kvinnor skapade mening av sin sjukdom. Data insamlades genom två till tre intervjuer om erfarenheter och förståelse av sjukdom. Efter ett år gjordes uppföljningsintervjuer. Sammanlagt genomfördes 25 intervjuer. Data analyserades med en kvalitativ metod och en grounded theory ansats (Strauss och Corbin, 1990). Via journaler insamlades data om vårdgivares bedömning.

#### *Resultat*

Hälsan beskrevs med kroppsliga symptom, emotionella, psykologiska och psykiatriska begrepp. Symtom gavs ofta kausala orsaksförklaringar och flera pågående förklaringar. Främst användes tre vårdresurser: sjukvården, alternativ vård och egenvård. Deltagarna hade av vårdgivare fått en psykologisk förklaring till sina besvär. I kontakt med sjukvården kom de flesta deltagarna att förändra uppfattningar och förklaringar. Från att ha förklarat kroppsliga symptom med kroppsliga orsaker hade emotionella och psykologiska orsaksförklaringar börjat beaktas. Psykologiska begrepp hade börjat uppfattas som verktyg i att förstå och ge nya möjligheter till vård. Den sociala kontexten upplevdes bidra till en förbättrad sjukdomsförståelse.

### **Studie II:**

Turkish Migrant Women Encountering Health Care in Stockholm. A Qualitative Study of Somatization and Illness Meaning. Publicerad i *Culture, Medicine and Psychiatry*, 24(4), 431- 452, 2000.

#### *Syfte och metod*

Studien syftar till att utforska hur 10 turkiskfödda kvinnor skapade mening av sin sjukdom. Data insamlades genom två till tre intervjuer om erfarenheter och förståelse av sjukdom. Efter ett år gjordes uppföljningsintervjuer. Sammanlagt genomfördes 29 intervjuer. Data analyserades med en kvalitativ metod och en grounded theory ansats (Strauss och Corbin, 1990). Via journaler insamlades data om vårdgivares bedömning.

### *Resultat*

Hälsan beskrevs med konkreta uttryck om kroppen, känslor, och den sociala livssituationen. Värk förlades ofta till ena halvan av kroppen och ofta användes hjärtat som ett uttryck för ohälsa. Deltagarnas sjukdomsförklaringar karakteriserades av att beskriva samband mellan hälsa och livssituation. Främst användes tre vårdresurser: sjukvård i Sverige, sjukvård i Turkiet och traditionell folklig vård. De flesta deltagarna hade mött vårdgivare som gett deras besvär en psykiatrisk förklaring. Psykiatriska förklaringar gavs ett mycket begränsat accepterande. Flera deltagare beskrev svårigheter i att förstå vårdgivare och behandling. Några upplevde positiva erfarenheter av att lära sig något nytt. Samtliga deltagare försökte, trots svårigheter, förstå vårdgivarnas budskap. Den sociala kontexten upplevdes bidra till socialt och emotionellt stöd.

### **Studie III:**

Restructuring Illness Meaning Through the Clinical Encounter: A process of Disruption and Coherence. Accepterad den 5 juni 2003 för publicering i *Culture, Medicine and Psychiatry*.

### *Syfte och metod*

Studien syftar till att utforska förändring av meningsskapande av sjukdom hos 10 turkiskfödda kvinnor. Data insamlades genom en sekundär analys av data insamlad för studie II samt genom nya intervjuer. Sammanlagt analyserades data från 37 intervjuer med en grounded theory ansats (Strauss och Corbin, 1990).

### *Resultat*

Förändring av meningsskapande inkluderade förluster av tidigare uppfattningar, förändringar i uttryck och i vårdanvändande samt en förskjutning mot en psykologisk och psykiatrisk förståelsemodell. Förändringsprocessen var komplicerad och innehöll kontinuitetsbrott. I sin vardag försökte kvinnorna överbrygga skillnader i sjukdomsuppfattningar. I detta hade de ett begränsat stöd från sin sociala kontext. Utifrån resultaten föreslås att Antonovskys (1988) begrepp om KASAM (en känsla av sammanhang) kan vara av betydelse för förändring av meningsskapande av sjukdom och att en känsla av sammanhang i förändringsprocessen kan ha betydelse för återhämtning.

#### **Studie IV:**

Making sense of different illness realities. Restructuring of illness meaning among Swedish-born women. (submitted).

##### *Syfte och metod*

Studien syftar till att utforska förändring av meningsskapande av sjukdom hos åtta svenskfödda kvinnor. Data insamlades genom en sekundär analys av data insamlad för studie I samt genom nya intervjuer. Sammanlagt analyserades data från 32 intervjuer med en grounded theory ansats (Strauss och Corbin, 1990).

##### *Resultat*

Förändring av meningsskapande inkluderade två tendenser, först ett accepterande av en psykologisk förklaring och senare ett fokus på stress och arbetssituation. Begreppet utbränd hade introducerats. Meningsskapande var en komplicerad, kontinuerlig och interaktiv process. I sin vardag försökte kvinnorna överbrygga skillnader i sjukdomsuppfattningar. I detta var den sociala kontexten ett viktigt stöd. Också utifrån dessa resultat föreslås att Antonovskys (1988) begrepp om KASAM (en känsla av sammanhang) kan vara av betydelse för förändring av meningsskapande av sjukdom.

#### **Studie V:**

In unfamiliar territory: caregivers' encounter with somatic communication of mental ill health in a multicultural community. (manuskript).

##### *Syfte och metod*

Studien syftar till att utforska vårdgivares erfarenheter av att, i en mångkulturell miljö, möta patienter som uttrycker psykisk ohälsa med kroppsliga symtom samt vårdgivares erfarenheter av att introducera sin professionella sjukdomsuppfattning till patienter. Data insamlades genom sju fokusgruppsintervjuer med personal i primärvård och psykiatri. Data analyserades i två steg, först en innehålls analys (content analysis) och därefter en analys med en grounded theory ansats (Strauss och Corbin, 1990).

##### *Resultat*

Kroppsliga symtom uppfattades av vårdgivarna som ett vanligt sätt att uttrycka psykisk ohälsa. Avseende patienter från den mångkulturella delen av området upplevde

vårdgivarna språkliga kommunikationsproblem och svårigheter att tolka uttryck för upplevd ohälsa. Vid introduktion av sjukdomsuppfattning saknades stöd i organisatoriska och kliniska modeller av att anpassa arbetet till den mångkulturella befolkningen och i att behandla psykisk ohälsa utanför psykiatrin. Individuellt försökte vårdgivarna att skapa en känsla av sammanhang mellan deras och patientens sjukdomsuppfattning.

### **Metodartikel VI:**

Focus Group Interview Research in Transcultural Psychiatry - Reflections on Research Experiences. Publicerad i *Transcultural Psychiatry*, 39(4), 485-501, 2002.

Studie VI är en metodologisk diskussion om att använda fokusgrupper som en forskningsmetod i transkulturell psykiatrisk forskning. Fokusgrupper är en ny metod i vårdforskning och innefattar såväl möjligheter som begränsningar i den kontext där den används.

### **Betydelse av resultat från studie I-V**

Resultaten från dessa studier visar på vikten av att behandlare tar del av patientens mening kopplat till sjukdomsupplevelse. Resultaten pekar på betydelsen av att patientens förändring av meningsskapande av upplevd sjukdom kan ske med en känsla av sammanhang till sjukdomsuttryck, upplevelse, förståelse och tidigare meningsskapande. Utifrån resultaten av dessa kvalitativa studier har utifrån ett patientperspektiv följande tre *hypoteser* avseende bemötande av psykisk ohälsa i mångkulturella vårdmiljöer formulerats:

- 1) Att skapa en känsla av sammanhang avseende upplevelse, uttryck, tidigare och ny mening given till sjukdomsupplevelse kan vara viktigt för den enskilde patientens återhämtningsförmåga.
- 2) Vårdkontakter som syftar till att förändra patienters meningsskapande av sjukdom behöver stödja patienten i att kunna skapa en känsla sammanhang mellan egen sjukdomsuppfattning och vårdgivares medicinska modell.
- 3) Patientens sjukdomsuppfattning behöver beaktas som en viktig samarbetsresurs till den medicinska förklaringsmodellen.

För fortsatt forskning visar resultaten från dessa studier på behovet av ett vidare utforskande av interaktionen mellan sjukvård och individer samt mellan sjukvård och

sociala och kulturella grupper. Detta är av betydelse för att förstå hur individer och grupper använder och hanterar vård och behandling i relation till återhämtningsförmåga. Denna typ av kunskap är av speciell betydelse för patienter som befinner sig i en immigrations situation, detta då immigration innebär uppbrott, förflyttning och nyomställning.

För personal i mångkulturella vårdmiljöer pekar resultaten från studierna på behovet av stöd från organisatoriska och kliniska modeller i att kunna anpassa arbetet till en mångkulturell befolkning och i att bemöta och behandla psykisk ohälsa utanför psykiatri.

**TÜRKÇE ÖZET**  
**(SUMMARY IN TURKISH)**













## BACKGROUND

*“I want to understand the world from your point of view. I want to know what you know in the way you know it. I want to understand the meaning of your experience, to walk in your shoes, to feel things as you feel them, to explain things as you explain them. Will you become my teacher and help me understand?”*

Spradley (1979, p. 34)

### Introduction

The general aim of this thesis is to explore, understand, and describe how a group of Swedish-born women and a group of Turkish-born women gave meaning to their illness. The participants were in contact with local health care in a multicultural area of Western Stockholm and had been assessed as somatizing by their caregivers. The definition adopted for somatization is a tendency to experience and communicate psychological and social distress in the form of physical symptoms and to seek medical help for them (Lipowski, 1987).

My research originated and started out from questions arising in my clinical work. This led to further questions raised during the research process. Working as a consultant psychiatrist in a multicultural area in Western Stockholm I got the impression that patients assessed as somatizing often gave their symptoms meanings that were unfamiliar to me. The research started with two studies exploring illness<sup>3</sup> meaning among ten Turkish-born and eight Swedish-born women, all assessed as somatizing by their caregivers. The two studies were completed in the form of two papers (Papers I and II) and a licentiate thesis, September 2000 (Bäärnhielm, 2000). Results from the studies showed that the participating women had been introduced to a “psychological language of distress” (see page 31) by their caregivers. Results pointed to the importance of further exploring how the participating women restructured illness meaning. The latter refers to how they received and incorporated their caregivers’ therapeutic intervention of introducing a psychological language of distress. Further results indicated the importance of gaining an insight into the caregivers’ experiences and in how they imparted their professional agenda of illness meaning.

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<sup>3</sup> Stewart and Weston (1995) refer to the conceptual distinction between disease (the pathological process) and illness (the unique experience of feeling unwell), first to have been clarified by Fabrega in 1978 in “Disease and social behaviour.”

The first two studies (Papers I and II) were followed by two studies exploring restructuring of illness meaning among the ten Turkish-born and the eight Swedish-born women, who had participated in the preceding studies exploring illness meaning. These subsequent studies are presented in Papers III and IV. A parallel study was carried out to explore experiences and meanings of encountering patients using a bodily idiom for emotionally distress among caregivers in the local area. Focus group interviews were used to collect data and the results are presented in Paper V. The Paper further explores the caregivers' experiences of imparting their professional agenda of illness meaning. Methodological challenges with analysing data collected in focus group interviews led to paper VI, reflecting on the significance of focus group research as a qualitative research method in transcultural psychiatry.

This thesis frame will present each study separately. The results of the studies will be summarised and discussed at the end. The thesis frame will follow the chronological order of the research. First, a presentation of the background to the research process. This includes comments on clinical experiences, Turkish immigration, and on immigration, health, mental ill health, and mental health care in a Swedish context. This is followed by a presentation of the theoretical framework, aims, methods, ethics and procedure of the studies. Theoretical framework, methodology and results are then discussed. Finally, the discussion includes concluding remarks as well as comments on the implications for practice and future research. The content of this thesis frame is restricted to the ambition of conveying a contextualised understanding of the research process. Much of the text of the my licentiate thesis (Bäärnhielm, 2000), in a revised form, is included in this thesis frame. The time schedule of the explorative studies was as follows:

## Time schedule for the explorative studies

### **1997-1999**

#### Study I - II

Study I - II: Initially, two to three explorative interviews with each participant about illness meanings, followed by diagnostic SCID interviews, survey of social situation, collecting of primary care medical records, (1997-1998).  
Follow-up interviews one year after the first interviews, (1998-1999).

### **2000**

Licentiate thesis

### **2001**

#### Study III -V

Study III – IV: Reanalysis of data collected for Study I and II and new explorative interviews.

Study V: Focus group interviews.

### **2002-2003**

Continued analysis and writing.

## **Clinical experiences**

In my former work as a consultant psychiatrist at Spånga psychiatric outpatient clinic, I encountered patients from the poor, deprived and multicultural areas of Rinkeby and Tensta in Western Stockholm. I met patients with a diversity of cultural backgrounds, ethnical affiliations, expressions of emotional distress, expectations of mental care, and pathways to care. Factors such as immigration, culture, different traditions and meanings were evident. I got the impression that patients often gave their suffering and illness another meaning than that attributed by my colleagues and myself. This applied to both our professional assessments as well as to our lay perspective. Patients assessed as somatizing seemed to form a core group in which there were conflicts between the meanings they gave to illness and the meanings given by professional caregivers. I also felt that the understanding of, and meanings given to, illness influenced the whole process of illness development, help seeking, presentation of suffering and symptoms, coping strategies, acceptable interaction with clinicians, and the outcome of the clinical encounter and recovery. This included gender differences.

Immigrant women with unexplained somatic symptoms, assessed as somatizing psychological or social distress into bodily symptoms, were often referred to the outpatient psychiatric clinic. On encountering these women I started to wonder about differences in meanings given to illness. I asked myself, “What does illness mean for you, how do you explain it, how do you understand it, how do you understand me, and how can we collaborate?” The strategies of clinical work did not focus on understanding the meaning of the patient, and its demands did not give me time to convey such questions to the patients or allow me to delve for knowledge beyond the everyday context. Fulfilling the most basic demands of the clinical work took so much time and energy that questions reflecting structures of the work became threats to the fragile order of things. My growing inquisitiveness about the perspective of the patient together with a heavy clinical workload, with limited space for reflection or development, provided the origin and background to the formulation of the two first studies exploring illness meaning (Papers I and II).

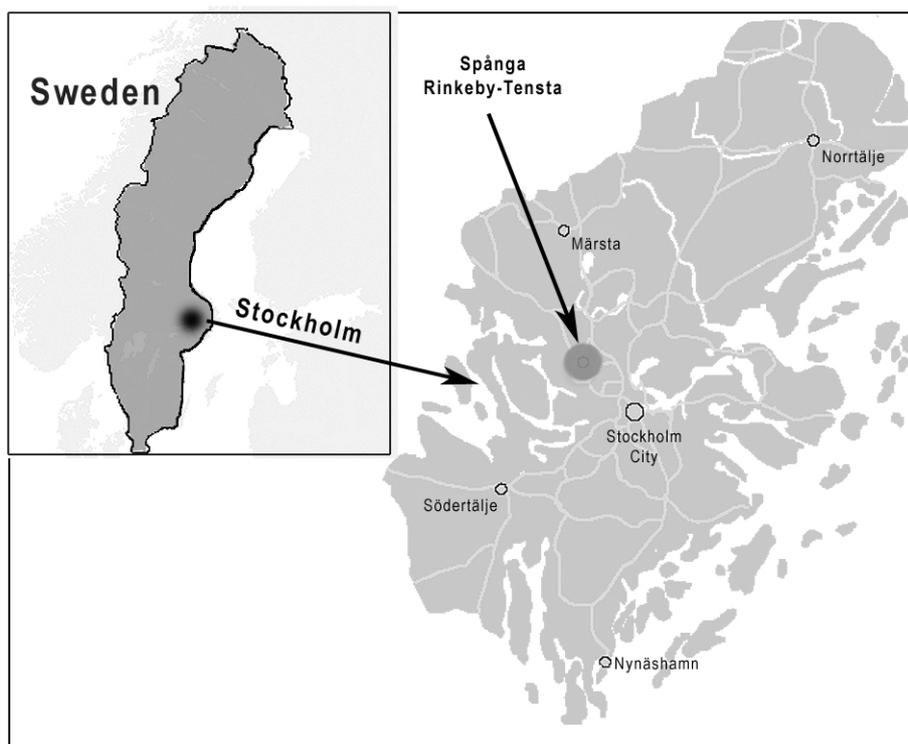
In addition to the first two studies (Papers I and II) I made two journeys to Turkey. The first journey was made before the start of the studies, in 1994, together with colleagues from Spånga psychiatric outpatient clinic. The journey was funded by Stockholm County Council. We visited psychiatric facilities in Istanbul and Ankara and also the Kulu district as well as the local hospital in Kulu. Many immigrants from

Turkey in Sweden, and in Western Stockholm, come from the Kulu district. During the journey we were informed about health care and mental health care delivery in the Turkish context and about health and mental health problems among returning immigrants from Western countries including Sweden. We were introduced to the importance, and local use, of traditional folk healing strategies and to how our Turkish colleagues collaborated with these traditions and with local healers.

The second journey was to Istanbul in 1998, during the studies, together with Solvig Ekblad, my scientific supervisor and four colleagues. This purpose of this trip was to learn about cognitive behavioural treatment for tortured refugees (Başoğlu et al., in press) and to meet Turkish colleagues and interview them about psychiatric care. Returning four years later gave me a somewhat different picture than that obtained on the first journey. This time, Turkish colleagues described how social and lay ideas, as well as attitudes, were changing. The experiences gained on the journeys influenced me to be attentive to the use of folk healing traditions and to the importance of the organisation of mental health care delivery. I also became more aware how changeable lay ideas, meanings and attitudes are over time. The journeys left me with the impression that immigration entails a special situation with regard to belonging – or not belonging - to contextual social and cultural webs of change in medical attitudes. This probably includes gender differences with regard to women’s role in the family and their social participation in society.

### **Clinical context and Turkish immigration to Sweden**

The clinic where I worked, Spånga psychiatric outpatient clinic, serves the geographical area Spånga in Western Stockholm (map of Spånga). All the studies of the thesis (I – V) have been carried out in this area. Spånga includes the three suburbs Spånga (its name is used for the whole area), Tensta and Rinkeby. The suburb of Spånga comprises a mainly Swedish-born population often living in detached and terraced houses. The multicultural suburbs Rinkeby and Tensta were built in the middle of the sixties as part of a programme for solving a major housing shortage. A majority of the patients coming to the clinic had an immigrant background (Bäärnhielm and Saers, 1998). At the start of the studies the major country of origin of the patients was Sweden followed by Turkey. In a study examining the local psychiatric outpatient clinic, Al-Saffar and Borgå (1995) found the diagnosis of “somatoform disorder” to be more common among immigrant patients than among Swedish-born patients.



*map of Spånga Rinkeby-Tensta*

*copyright Gunilla Andersson*

In Stockholm, 17.6 % of the population is foreign born and represents 179 countries (Statistik om Stockholms län, 2001). The largest group comprises immigrants from Finland and the second largest group from Turkey with 19 415 persons of whom 4 352 reside in the Western part of Stockholm (Statistik om Stockholms län, 2001). When the studies started in 1997, in Rinkeby alone, the inhabitants originated from 125 different countries (Stockholms stad USK, 1997). In 1999, 72.4% of the population in Rinkeby and 65.8 % in Tensta had been born in a foreign country (Stockholms stad USK, 2000). The largest group of migrants in this local area, at the time these studies started, comprised immigrants from Turkey (Stockholms Stad USK, 1999). Turkish-born migrants in the local area were labour migrants and refugees with ethnic affiliations to major groups such as, Turks, Kurds and Assyrians. Many of the migrants had come, as mentioned above, from the Kulu district in Turkey.

Kulu is a district encompassing a group of villages on the Anatolian tableland 100 km. south of Ankara along the main road leading south to Konya. The population of Kulu is ethnically diverse, being affiliated to Turks, Turkmen, Kurds and Tartars (Lundberg and Svanberg, 1992). The immigration from Kulu to Sweden started as a part of the Turkish exodus to Western Europe in the 1960s and 1970s. It started as a spontaneous chain-migration (Lundberg, 1991) and has now become part of

contemporary Swedish history. The migration started as a labour migration and has continued, now mainly in the form of family reunions and marriage. Many of the Kulu migrants have settled down in specific suburban areas in Stockholm with low socio-economic levels like Rinkeby and Tensta. In total there are about 32 000 immigrants from Turkey in the whole of Sweden. This makes Turkish-born immigrants the tenth largest national group and the third largest non-European group in Sweden (Statistic Sweden, 2001).

### **Immigration, health and mental ill health in Sweden**

The current change of Sweden into a multicultural society has placed new demands on the health care system. Of the Swedish population, eleven per cent is foreign-born (Statistic Sweden, 2001). Since World War II Sweden has received waves of refugees from devastated areas of the world. The active import of labour migrants started at the end of the forties only to cease almost completely in the beginning of the seventies. Residents of other Nordic countries were exempt from this immigration restriction (Sundquist, 1998). Migration due to family reunions continued. In the 1970s there was a wave of refugees from Latin-America, in the 1980s from Eastern Africa and the Middle East. Since the 1990s migration to Sweden has been dominated by the wars in the Balkans and in the Middle East.

Immigrants in Sweden are a very heterogeneous group with regard to living conditions and health. In a report about the public health situation in Sweden, the National Committee for Public Health (SOU, 1998:43) summarised the 90s by suggesting that a trend had been broken with regard to the development of the welfare of the population. The groups that, already in the middle of the 80s, were experiencing a disadvantaged situation, had seen a deterioration during the 90s, especially young people, single parents, long-term sick-listed and some immigrant groups. Social differences were noticed to be generally greater in large cities than in less densely populated areas, and differences in health and lifestyle between some immigrant groups and Swedes appeared to be pronounced.

Concerning research about immigrants and health and mental ill health in Sweden, most studies focus on specific geographical areas. In an epidemiological study of self-reported health, Sundquist and Johansson (1997) found that being foreign born was strongly associated with limiting long-term illness when controlling for social, material and lifestyle factors. In a population-based study of Latin American refugees and

Swedish controls, it was found that the strongest independent risk mediator for mental illness was ethnicity (Sundquist, 1993). In a qualitative study among Latin American refugees, either living in exile in Sweden or repatriated, it was found that during exile the cultural barrier, social degradation, guilt, social passivity, and ideological alienation caused a changed identity and low control, which increased the vulnerability to psychological distress and physical disease (Sundquist et al., 1995). A pilot study about the relationship between traumatic life events, symptoms and the sense of coherence (SOC) meaningfulness subscale among a group of refugee and immigrant patients at a psychiatric outpatient clinic in a southern suburb of Stockholm, showed that low SOC meaningfulness was associated with mental distress and impaired functioning (Ekblad and Wennström, 1997).

#### *Acculturation and the role of the immigration context in health*

Acculturation and the immigration context may have an important role in the health situation of immigrants. Immigration involves being uprooted, dislocated and relocated, and is a potentially stressful life situation. It entails acculturation to a new host society. Berry and Kim (1988) define acculturation as the culture change that results from continuous, first-hand contact between two cultural groups. The acculturation process involves potential changes of identity and a questioning of the relationship to the new host society. Marginalisation exposes the individual to a highly stressful crisis, and Berry and Kim (1988) suggest that it is amongst marginalised migrants that the poorest mental health is to be expected. The importance of social origin for mental ill health is documented in the World Mental Health Report (Desjarlais et al., 1996).

The role of the immigration context for health has been analysed in some recent Swedish and other Scandinavian studies. In a prospective study of life events in refugees during reception from Iraq in Stockholm, Söndergaard, Ekblad and Theorell (2001) found the number of negative life events in the host country to be associated with self-rated deteriorated health. In his thesis about the prevalence of PTSD and life events among recently resettled refugees from Iraq, Söndergaard (2002) concludes that recent life events are important for present health status and interact with previous traumatic experiences. In a study of foreign-born immigrants, Sundquist et al. (2000) found a low sense of coherence, poor acculturation (men only), poor sense of control, and economic difficulties to be risk factors for psychological distress. These factors were also found to be stronger than exposure to violence before migration.

Bayard-Burfield (1999) analysed the influence of immigration status, acculturation and socio-economic and psychosocial factors on a variety of outcome variables: self-reported illness, intake of benzodiazepines and psychotropic drugs, suicide attempts, all-causes of mortality and violent death. It was found that immigrants had twice the risk of self-reported long-standing psychiatric illness, psychological distress and psychosomatic complaints, particularly among South European labour migrants, refugees from Iran, Chile, Turkey and Poland. In Norway, a cohort of Vietnamese refugees was studied and three years after immigration the effects of trauma were found to be long lasting and compounded by adverse factors in exile (Hauff and Valgum, 1995). For refugees referred to a psychiatric outpatient clinic in Oslo, it was found that past traumatic stressors and current existence in exile constituted independent risk factors (Lavik et al., 1996). For a further review, see Silove and Ekblad (2002).

#### *Immigrants and musculoskeletal pain conditions*

There are some studies focusing on musculoskeletal pain conditions for immigrants in Sweden. Studying primary health care utilisation in a suburban area in the eastern part of Lund in the south of Sweden, Sundquist, Rosén and Johansson (1994) found that being born outside Sweden was associated with increased prevalence of musculoskeletal disease, compared with people born in Sweden. Soares and Grossi (1999a) examined differences between immigrant and Swedish patients with musculoskeletal pain, concerning demographic and financial variables, pain parameters, job strain, coping styles and psychological symptoms in a suburban low status area. The findings showed that immigrants relied more often on benefits, were more concerned with their financial situation, had longer periods of sick-leave, felt more disabled, reported more job strain, relied more on passive coping strategies and were more emotionally distressed. They showed more symptoms of burnout, anxiety, depression, post-traumatic stress reactions, and lower self-confidence. The authors concluded that the immigrant patients lived under more strained psychosocial conditions and experienced a deeper impact of pain compared to their Swedish counterparts.

Examining differences between Turkish and Swedish patients with musculoskeletal pain in a low status suburban area, Soares and Grossi (1999b) found that the Turkish patients were exposed to a greater variety of psychosocial stressors, were more negatively affected by their pain conditions, had poorer mental health and less ability to cope with pain. In a thesis about immigrants from a primary care area perspective,

testing the effect on well-being and sickness certification of different therapeutic approaches, Löfvander (1997) explored the phenomena of illness, disease and sickness certification. The research, carried out in the same geographical area as the studies of this thesis, concluded that for participating immigrant patients pain anxiety was the core of illness, disease and sickness pattern. Among a group of Greek immigrant patients pain was considered as something dangerous, leading to permanent disability if the sufferer should deliberately aggravate pain, and there was little confidence in doctors' examinations and physiotherapy.

### *Women, immigration and health*

There are facts pointing to a vulnerable health situation for immigrant women in Sweden. Regarding women's health situation in general, the 1997 Public Health report (SoS, 1997) claimed that in Sweden, during the eighties, there had been a greater general improvement in health among men than among women. The report stated that with regard to women's health the impact of social differences had increased during the 80s (SoS, 1997). In poor and deprived areas of the major cities, it was evident that women's health had deteriorated between the middle of the eighties and the middle of the nineties. There had been a concentration of immigrants in this type of area, especially those newly-arrived, and an increase in mental ill health among women particularly with regard to malaise and anxiety, especially among foreign-born women (SoS, 1997).

For some groups of immigrant women, there is evidence to suggest poorer perceived mental health than among their Swedish-born counterparts (SOU, 1998:43). In a study of living conditions and health for four immigrant groups from Chile, Iran, Poland and Turkey, data were collected from mainly personal interviews and the results compared with native-born Swedes (Invandrarprojektet-rapport, 1998). The basis of the study was Statistic Sweden's investigation of living conditions (ULF)<sup>4</sup>. Interviews were conducted with 1 980 persons, who had been in the age range 20-44 on their arrival in Sweden. Data were collected mainly by personal interviews. The results suggested major differences in the state of health of the immigrant groups and the native-born population. The four immigrant groups perceived their health as poor compared to native-born Swedes. The women from Chile, Iran and Turkey had a significantly poorer state of

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<sup>4</sup> ULF (Undersökning om levnadsförhållanden) The Swedish Survey of Living Conditions began in 1974 and was conducted by Statistic Sweden. ULF is a series of annual surveys of living conditions providing a basis for public debate and social and political reforms. Since 1979 the main themes have been: social relations, work, health and physical environment (Bayard-Burfield, 1999).

perceived health than the men and the Swedish-born women. Perceived symptoms of mental ill health such as, sleeping problems, headache, considerable distress due to malaise and anxiety occurred much more frequently among the immigrant groups than among the Swedish-born subjects. This finding about immigrant women and health is confirmed in a local study in Västerås where perceived health was poorer in a group of refugee women than among men. After six years in Sweden these women's perceived health had deteriorated, especially with regard to somatic and/or psychosomatic symptoms (Kjellin et al., 1992). Exploring how birthplace and socio-economic status interact in attempted suicide among 4.5 million Swedish persons aged 25 to 64 years, Westman et al. (2003) found place of birth, socio-economic status, and sex to be associated with attempted suicide. Women born in Latin America, Asia, and Eastern Europe had high hazard ratios of attempted suicide.

### **Immigration and mental health care utilisation**

The health and mental health care system in Sweden is encountering an increasingly cultural diverse population. However, there is a paucity of studies in Sweden regarding cultural background and utilisation of mental health care. In Stockholm County, migrants from non-Scandinavian countries have demonstrated lower psychiatric care utilisation rates than the rest of the County's population (Diderichsen and Varde, 1996). A diverse pattern of psychiatric mental health care utilisation regarding different ethnical groups and genders has been established for the County of Stockholm (Oxenstierna, 1998). Utilisation of private care, care in country of origin or elsewhere is unknown. In a psychiatric setting situated in a multicultural area in the Southern part of Stockholm, Lindencrona, Ekblad and Charry (2001) conducted a participatory action research study focusing on the socio-ecology of psychiatric outpatients with severe war-related trauma. The study concluded that the services provided by the studied community mental health centre have to be redesigned and a system of intersectoral collaboration should be developed in co-operation with representatives from community services and businesses and the patients themselves.

Mental health care utilisation, immigration and suicide have been addressed in some theses. In an epidemiological study of suicide, Ferrarda-Noli (1994) considered ethnicity, psychiatric, psychosocial and forensic factors. A significant overall overrepresentation of immigrants was found in the total number of suicides and cases of undetermined suicide and accident. Also, a covariation was found between suicide and

immigrant status, unfavourable socio-economic conditions and lack of psychiatric care. Immigrant groups were under-represented among patients seeking psychiatric counselling and even more so among those admitted for inpatient mental health care. In a thesis about migration, health and suicide, Johansson (1997) found ethnicity to be an independent risk factor for suicide and for high psychiatric admission rates. Bayard-Burfield et al. (1999) found, among patients attending Lund University Hospital, a higher risk of attempted suicide among foreign-born than among Swedish-born individuals. These facts suggest that there are problems within health care in meeting mental health needs and communication of distress among the immigrant population and that there may be a potential under-assessment of mental illness and under-utilisation of mental health care among some groups in the immigrant population. There are international epidemiological studies examining the impact of immigration and culture on mental health care utilisation at a population level. Some examples will follow. In an explorative study about the relationship between birthplace and the treated prevalence of mental disorders in Australia it was found that country of origin had a significant effect on the treated prevalence of mental disorders (Stuart, Klimidis and Minas, 1998). An epidemiological and ethnographic study in a multi-ethnic area in Montreal Canada suggested a substantial under-utilisation of mental health services by immigrant groups (Kirmayer et al., 1996). The need to focus research on the dynamic interaction between cultural group and psychiatric service is suggested by Watters (1996) in his exploration and examination of the implications which specific representation may have on the mental services Asians receive in British psychiatry. Qualitative studies can contribute to understandings of local interaction between health care and cultural groups. An example of this is an explorative qualitative study conducted in Britain by Cinnirella and Loewenthal (1999) focusing on mental health beliefs, causes and cures, coping and help-seeking, and stereotypes of health professionals, in five different cultural-religious groups of women (White Christian, Pakistani Muslim, Indian Hindu, Orthodox Jewish and Afro-Caribbean Christian). It was found that across all groups, except White Christians, there was fear of being misunderstood by outgroup health professionals. Among Afro-Caribbean and Pakistani Muslim participants there was evidence of a community stigma associated with mental illness, leading to a preference for private coping strategies. This type of contextualised knowledge can be useful in improving local health care responses to local populations.

## THEORETICAL FRAMEWORK

*“we express our distress through bodily idioms that are both peculiar to distinctive cultural worlds and constrained by our shared human condition.”*

Kleinman (1988, p. xiii)

The studies in this thesis explore meaning, meaning making and interaction between two cultural groups of female patients, assessed as somatizing, and caregivers in a multicultural area of Stockholm. The theoretical framework of the studies includes, culture and formulation of emotional distress, using a bodily idiom for emotional distress, explanatory models and illness meaning, clinical transaction of meanings, and the sense of coherence concept. The presentation of the theoretical framework is restricted to that of anchoring the studies to theory.

### **Culture and formulation of emotional distress**

The introduction to DSM-IV, Diagnostic and Statistical Manual of Mental Disorders (APA, 1994) suggests that symptoms and the course of a number of DSM-IV disorders are influenced by cultural and ethnic factors. To enhance its applicability for diverse cultural contexts, the manual includes three types of information specifically related to cultural considerations: 1) a discussion in the text of cultural variations in the clinical presentations of those disorders that have been included in the DSM-IV Classification; 2) a description of culture-bound syndromes<sup>5</sup> (DSM-IV, Appendix I, 1994) and, 3) an outline for cultural formulation designed to assist the clinician in systematically evaluating and reporting the impact of the individual’s cultural context (DSM-IV, Appendix I, 1994). For psychiatric assessment and diagnosis, Mezzich et al. (1999, p. 458) suggest that culture is involved in at least five ways: shaping phenomenology of symptoms, manifested through ethnopsychiatric diagnostic rationales and practice of grouping symptoms, matrix for the interpersonal situation of the diagnostic interview, the dynamics of cross-cultural work for refining diagnostic categories and practise, and the overall conceptualisation of diagnostic systems.

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<sup>5</sup> The term culture-bound syndrome denotes recurrent, locality-specific patterns of aberrant behaviour and troubling experiences that may or may not be linked to a particular DSM-IV diagnostic category. Many of these patterns are indigenously considered to be “illnesses,” or at least affiliations, and most have local names (DSM-IV, Appendix I, Glossary of Culture-Bound Syndromes, 1994).

### *The concept of culture*

There are various definitions of the concept of culture, and corresponding ideas about the role of culture in the formulation of emotional distress. The term culture is said to be one of the two or three most complex words in the English language (Eagleton, 2000). Defining culture, Kleinman (1996) points to the notion that culture is constituted by, and in turn constitutes, local worlds of everyday experience. Kleinman (1996, p. 16) says: “That is to say, culture is built up (‘realized’) out of the everyday patterns of daily life activities - common sense, communication with others, and the routine rhythms and rituals of community life that are taken for granted - which reciprocally reflect the pattering downward of social relations by shared symbolic apparatuses - language, aesthetic sensibility, and core value orientations conveyed by master metaphors.” Kleinman (1996, p. 16) continues, “Thus, the locus of culture is not to be the mind of the isolated person, but the interconnected body/self of groups: families, work settings, networks, whole communities.”

Kleinman states that in the local worlds, experience is an interpersonal flow of communication, interaction and negotiation *that are social and not individual* (my italics). In this perspective culture is something that affects health promotion, local clinical work, psychiatric assessment of disorders, and coping processes. Good (1997) proposes that culture and reality should be conceived as being embedded in activity, in interpretative practices of members of a society interacting with the social and empirical world to formulate and apprehend reality in distinctive ways. With these perspectives culture becomes a part of the everyday process of formulating distress and treatment, and not only relevant for exotic diagnoses or treatments.

Discussing culture in relation to context, Caracci (2002) proposes that the two concepts are overlapping. Caracci (2002) suggests that the concept of context is dynamic, is based on relations occurring as necessary but not sufficient conditions, and is a medium for a phenomenon that may require many variables to occur at the same time.

### *Culture and idioms of distress*

Kleinman (1988) proposes that we express distress through expressions both peculiar to cultural worlds and constrained by our shared human condition. Several attempts have been made to try to formulate the role of culture in the process that ranges from experiencing to expressing emotional distress in terms of symptoms. Good (1996)

suggests that the role of culture is to enter and shape the attention to, and communication of, disordered experiences, but not at the more basic level of symptom formation. Analysing the role of culture for transformation of affects, Obeyesekere (1985, p. 147) formulates the role of culture as: “The *work of culture* is the process whereby painful motives and affects such as those occurring in depression are transformed into publicly accepted sets of meanings and symbols.”

Analysing different distress responses, Carr and Vitaliano (1985) hypothesise, for example, that depression and the culture bound syndrome amok<sup>6</sup> are related and are to be found among the several alternative distress responses individuals may make to aversive conditions. They further suggest that specific behavioural responses represent a final common pathway of multiple aetiological determinants, among them, environmental, biological, psychological, cognitive, and socio-cultural factors. Similar cognitive aspects in the role of culture are proposed by Rogler (1996) who points to culture as having a mediating function in the proclivity of expressing emotional distress through its normative definitions of what is desirable or undesirable. Manson (1996) also suggests that culture has an organising role in the manifestation and interpretation of emotional stimulus. Angel and Thoits (1987) hypothesise the existence of learned cognitive structures, through which physical experiences are filtered and influence the interpretation of deviations from culturally defined physical and mental health norms. Discussing this in relation to immigration, Angel and Thoits (1987) propose that the specific situation for immigrants is one of having to restructure cognitive categorisations, to reorder their cognitive structures to conform to those which are consensually validated in the host society.

Emotional distress may be expressed in many ways. Avoidance of the open expression of emotions can be one normative ideal (White, 1982; Jaranson, Forbes Martin and Ekblad, 2000). Somatic symptoms can be a culturally appropriate way of articulating distress. Helman (1998) uses the expression “*language of distress*” to describe how different social and cultural groups communicate their suffering to others, including doctors. Helman describes how different social and cultural groups may utilise different languages of distress, verbal or non-verbal and the problems when clinicians fail in decoding them. Nichter (1981) has introduced the expression “*idioms of distress*”.

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<sup>6</sup> Amok, is a dissociative episode characterised by a period of brooding followed by an outburst of violent, aggressive, or homicidal behaviour directed at people and objects. The term was originally reported from Malaysia (DSM-IV, Appendix I, Glossary of Culture-Bound Syndromes, 1994).

This refers to ethnopsychiatric phenomena underscoring symbolic and affective associations which take on contextual meaning in relation to particular stressors, the availability and social ramifications of engaging alternative expressive modes, and the communicative power of these modes given intervening variables and the responsiveness of concerned others. Nichter suggests that when investigating the use of a particular idiom of expression it is necessary to locate it historically with respect to changing social conditions.

The first four studies of this thesis (Papers I-IV) focus on the participating patients' illness meaning and their restructuring of the same. The caregivers' perspective is described briefly with reference to data from medical records and from the patients' perspective. In the two first studies (Papers I-II), the caregivers' message is described using the all-embracing term "psychological agenda". The latter comes from patient-centred medicine (Levenstein, McCracken, McWhinney, Stewart and Brown, 1986). In the two later studies (Papers III-IV), Helman's (1998) term "psychological language of distress" is used. That these two terms encompass both psychological as well as psychiatric factors is clarified in Papers III and IV. Throughout this thesis these all-embracing terms have been clarified to the context in which they are used, for example whether it is a matter of a psychiatric or a psychological attribution.

### **Using a bodily idiom for emotional distress**

Somatic symptoms are a common global way of clinically presenting emotional distress (Isaac, Janca and Orley, 1996; Kirmayer, 1984). There are epidemiological studies pointing to an association between psychological distress and somatic symptoms (Katon et al., 1991; Isaac, Janca and Orley, 1996; Simon and VonKorff, 1991; Simon et al., 1996; 1999; Kroenke et al., 1997). The term somatization has several distinct meanings and is often used ambiguously (Parker, Gladstone and Chee, 2001). The term somatization is used clinically in several conceptually distinct ways: to refer to a family of psychiatric disorders, to a process of transforming or transducing psychological conflicts into bodily symptoms, and to describe a pattern of illness behaviour in which somatic symptoms are presented to the exclusion or eclipse of emotional distress and social problems (Kirmayer, Dao and Smith, 1998). In his book *The Illness Narratives* (1988, p. 57), Kleinman defines somatization, as "the communication of personal and interpersonal problems in a physical idiom of distress and a pattern of behaviour that emphasizes the seeking of medical help." In later works, Kleinman's definition has

changed from the idea of a particular idiom to regarding it as more normative and says, “Somatization seems normative and often normal; it is not so much a substitution for something more basic as it is a basic way of being-in-the-world” (Kleinman, 1995, p. 9). Kleinman suggests somatic modes of experience to be better understood in a “sociosomatic” language (Kleinman and Becker, 1998).

The studies in this thesis have focused on patients using a bodily idiom for emotional distress, and the concept of somatization has been used. The definition for somatization adopted for the first studies of this thesis exploring illness meaning (Studies I and II), and retained in the later studies exploring restructuring of illness meaning (Studies III and IV), was: somatization as a tendency to experience and communicate psychological and social distress in the form of physical symptoms, and to seek medical help for them (Lipowski, 1987). The definition was used as a selection criterion for recruiting patients from caregivers in local medical settings. The adopted definition reflects my view at the start of the studies but also the local caregiver assessment of the participating patients’ distress.

#### *Historical reflections on body mind dualism*

The concept of somatization has historical roots in a long Western history of mind-body dualism (Manson, 1996; Kirmayer, 1996; Fabrega, 1990). The Western philosophy of mind body dualism can be traced back to Platon, Hippocrates, Galen (see page 73), and to the French philosopher Descartes (Cartesius)<sup>7</sup>. According to Ackerknecht (1982), Greco-Roman medicine was radically somatic, something new and opposed to all previous supernaturalistic beliefs, before Hippocrates and Galen. Ackerknecht points to the importance of Galen’s system of notions, in which he created a concept by directing attention to “passions”<sup>8</sup>. Galen has had a great influence on Western medical traditions. A principal point in Descartes’ theory of knowledge is the thesis “cogito, ergo sum” (I think, therefore I am). This means that spiritual life is more certain than the material (Russel, 1994).

Discussing historical roots of mind-body dualism, Bullington (1999) states that dualism has infiltrated early Christian thinking and that of theologians, and that dualistic concepts of man may be found as early as 3000 BC in Egyptian hieroglyphics.

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<sup>7</sup> Descartes (1596-1650), by Russel (1994) considered to be the founder of modern philosophy.

<sup>8</sup> According to Ackerknecht, passions were the sixth of the six non-natural causes of disease in the Galenic system and a product of the vital soul and discussed earlier by Platon and Aristotele (Ackerknecht, 1982).

Reviewing literature about psychiatric illness and stigma in great non-Western medical traditions<sup>9</sup> (Islam, China and India), Fabrega (1991) finds the medical systems not to be differentiated along psychiatric versus non-psychiatric lines, and to handle illness in a psychosomatic/somatopsychic “integrated” way. Fabrega (1990) sees a postulate of mind/body correspondence and associations as integral to basic Western cultural assumptions regarding psychological experience and behaviour that are deeply embedded in European history.

### *Somatization versus psychologization*

White (1982) suggests that the psychological and psycho-somatic mode of reasoning found in Western cultures is unusual in the world’s popular and traditional systems of beliefs. White links psychologization to the Western concept of the person and argues that investigations of somatization should proceed alongside investigations of psychologization. Kleinman and Kleinman (1985) propose that the process of psychologization has been related to the cultural transformation shaped by modernism. With regard to clinical assessment, Epstein et al. (1999) point to the construct of the concept somatization as artificially separating bodily and psychological symptoms that patients experience as a unified whole. Kirmayer (1984) proposes somatization as one contemporary reflection of the conflict between personal and professional perceptions of distress. In a later study Kirmayer and Young (1998) suggest that to introduce a psychological language as a way of understanding a problem is to introduce culture-specific concepts of the person, which may conflict with the values and perspectives of the patients’ culture of origin, so creating new dilemmas for them.

Somatization can be viewed as a process rather than a category (Murphy, 1989). Somatization is suggested to have an interactional mechanism involving both the patient and the response of the clinician (Goldberg and Bridges, 1988). Littlewood and Lipsedge (1993) propose that it is easier for a clinician confronted with an emotionally distant patient to understand him/her in organic terms. There are studies pointing to difficulties and failures in primary care to recognise somatic expressions of common psychiatric illness such as anxiety and depression (Bridges and Goldberg, 1985; Kirmayer et al., 1993; Bodlund et al., 1999). In an international study of the correlation between somatic

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<sup>9</sup> Fabrega refers to the existence of three traditions (Islam, China and India) of non-Western medicine that represent ancient, literate, professional, and comprehensive accounts of health and illness. These are to be found in Islam, China, and India (Fabrega, 1991).

symptoms and depression, Simon et al. (1999) found that a somatic presentation was more common at centres (15 centres in 14 countries, in five continents) where patients lacked an ongoing relationship with a primary care physician than at centres where most patients had a personal physician. Furthermore, it was found that the frequency of somatic symptoms varied depending on how somatization was defined and with substantial variation in how frequently patients with depression presented with strictly somatic symptoms. It was suggested the variations might be characteristics of physicians and health care systems, as well as cultural differences among patients.

It is hypothesised that somatization may have an adaptive advantage, with a blame-avoiding function, saving patients from a more severe depression. However, the disadvantages include the risk of it becoming chronic and difficult to treat (Goldberg and Bridges, 1988; Bridges et al., 1991). Kleinman (1980) has suggested that keeping the intensity of distress relatively undifferentiated by somatic reference helps distance distress feelings and focus concern elsewhere as a coping strategy. There are facts suggesting that attributing one's problem to a mental illness as opposed to a 'physical, medical, or biological' condition may reduce subjective quality of life for persons with schizophrenia (Mechanic et al., 1994).

Somatization is sometimes linked to alexithymia. Taylor (1984) defined alexithymia as a specific disturbance in psychic functioning, characterised by difficulties in the capacity to verbalise affect and to elaborate fantasies. Alexithymia denoting a specific disturbance in an individual's functioning is primarily manifested in communicative style and with an impaired capacity for empathy. The concept of alexithymia has also been linked to patients having a reality based, concrete cognitive style (Lesser and Lesser, 1983). In a recent thesis, Posse (2002) found a prevalence of 20% for alexithymia in a primary care population and a significant association with advanced age, low educational level, and male gender. High scores for alexithymia were associated with somatic anxiety, psychastenia, and irritability. Taylor (1984) suggests a frequent presence of alexithymic characteristics for patients with somatoform disorders. However, there are studies pointing to an independency between alexithymia and somatization (Bach et al., 1994; Bach et al., 1996). The studies of the present thesis do not address alexithymia, as the general aim was to explore meaning from participants' own perspective.

### *Decoding meanings of somatic symptoms*

Cultural factors may influence meanings attached to somatic symptoms and the likelihood of presentation to health care (Simon et al., 1996). Discussing depression, Good et al. (1985) points to the importance of the cultural meanings associated with experience. Analysing Iranian depressive illness and dysphoric affect, Good et al. (1985) point to the problems experienced by Iranian patients in America when their symptoms are interpreted narrowly without reference to cultural aspects. With regard to Iranians suffering from depressive illness, Good et al. (1985, p. 393) says: “In American clinical settings, they are often communicated as symptoms or complaints; because clinicians are unaware of the syndromes of meaning associated with each of these complaints, they often interpret them narrowly as isolated psychiatric symptoms (‘heart palpitations’, ‘anxiety’) and fail to pursue their cultural significances.”

Studying the cultural experience and meaning of depression amongst white Britons in London, Jadhav, Weiss and Littlewood (2001) found that somatic idioms of depression, although not spontaneously reported, were frequently reported when specially probed. This contrasted with the situation in Bangalore in India where somatic symptoms were reported spontaneously and psychological symptoms acknowledged on probing. Comparing symptomatology of depression in outpatient samples in Britain and Turkey, Uluşahin, Başoğlu and Paykel (1994) found higher mean ratings for core depressive symptoms in the British sample and higher ratings in the Turkish sample for symptoms reflecting somatization. It was suggested that the findings indicated some cultural similarities in the symptoms of depression but also the predominant mode of expression.

Mirdal (1985) interviewed immigrant women in Denmark (with no cases of severe psychopathology) about their own evaluation of their physical, psychological and social conditions in their host country. She found that all complaints were of a somatic character with the exception of “tightness”, which had both somatic and psychic components. In order to understand the women, Mirdal points to sex roles and language. Mirdal suggests that in a very restricted environment focusing on illness may become a way to keep oneself alive and that illness may provide a socially approved way of obtaining relief from oppressing conditions. Mirdal also suggests that the structure of the Turkish language adapts itself to the expression of distress in terms of illness, which in turn is a culturally comprehensible alarm signal which alleviates oppression. Regarding clinical care, Kirmayer (2001) suggests that clinicians must learn to decode the

meanings of somatic symptoms, which are not simply indices of disease or disorder but part of a language of distress with interpersonal and wider social meanings.

### **Explanatory models, illness meaning and clinical transaction of meanings**

In exploring patients' meaning, restructuring of illness meaning, and caregivers' meaning, these studies have been inspired by the explanatory model (EM) perspective developed by the psychiatrist and medical anthropologist Arthur Kleinman. With the explanatory model perspective, Kleinman (1978) has directed attention to eliciting the cognitive aspects of patients' understanding of their illness and their response to clinical interventions. Kleinman says that the explanatory model framework provides the clinician with an expeditious practical method for gaining access to meanings of distinct importance for care.

In 1988, Kleinman defined EM as "the notions that patients, families, and practitioners have about a specific illness episode" (p. 121) and likens them to "cognitive maps" (p.122). In an earlier piece of work, Kleinman (1978) claimed that EMs contain any or all of the following five issues: aetiology; onset of symptoms; pathophysiology; course of sickness; and treatment and that they may be elicited from practitioners, patients, and family members for particular sickness episodes. He pointed to EMs as historical and socio-political products and suggested that the opinion that health care relationships might be studied and compared as transactions between different EMs and the cognitive systems and social structural positions to which they are attached. Kleinman further suggested that EMs could be used to construct different clinical realities for the same sickness episode, which in turn are reflected in discrepant expectations and miscommunication, and ultimately in poor care. Discussing the EM approach Kleinman (1981) states that illness is inseparable from the network of meanings within which it is experienced and treated, and that these meanings are changing, usually ambiguous and frequently tacit.

The EM perspective has had a great impact on transcultural research. De Jong and Van Ommeren (2002) suggest it to have been applied in three ways: (i) to specify semantic networks linking the experience of patients, healers, and other concerned parties (ii) to refer to perceived causes of illness and (iii) to look at the 'cognitive distance' between patients and healers. The EM perspective has been criticised for trying to explain the surface meaning in terms of a single set of underlying cognitive structures. Young (1982) argues that informants' statements juxtapose different kinds of

knowledge, and he outlines an alternative scheme for identifying the different kinds of medical knowledge that appear in people's statements, in which he regards explanatory models as one of several possible forms of theoretical knowledge. Young (1982) introduces the concepts "prototypes" and "chain complex" to describe how people organise the events and circumstances they are experiencing. "Prototypes" are described as a form of theoretical knowledge but without the strongly causal propositions of the EMs and limited to a small circle of people. "Chain complex" is formulated as strings of empirical events, sensations, symptoms, etc., which cohere and persist in the mind. Young considers (1982) informants' statements about sickness as occasional products of a combination of loosely connected EMs, prototypical experiences and chain complex.

#### *Illness meaning and clinical transaction of meanings*

The EM model directs attention not only to the importance of cognitively eliciting patients' understanding of their illness but also to their response to clinical interventions. Kleinman (1980, pp. 111 - 112) conceptualises the patient-doctor relationship as a dynamic transaction between EMs and points to the asymmetry in the interaction. He writes, "in clinical transactions, practitioners commonly do not elicit the patient's EM but spontaneously transmit at least part of their own EM. Whereas patients frequently do not disclose their own EM, they may elicit the practitioners' EMs." With the EM framework Kleinman points to the significance of examining what happens in the interaction between patients and professionals in care. The importance of concordance between patients' and professionals' EM have been shown to be important for patients' satisfaction with psychiatric care (Callan and Littlewood, 1998).

The model adopted for the presentation of the two first studies (Papers I and II) was that of different agendas for understanding, i.e. the agenda of the clinician and the agenda of the patient. This is a model used in the patient-centred method for family medicine to describe the clinician's twofold task of understanding the illness and the patient. Weston and Brown (1995) describe the patient-centred model and method to be introduced by Balint and colleagues, developed by Levenstein, and consisting of six interconnecting components: 1) Exploring both disease and the illness experience. 2) Understanding the whole person. 3) Finding common ground. 4) Incorporating prevention and health promotion. 5) Enhancing the patient-doctor relationship. 6) Being realistic. The model of different agendas for understanding entails the essence of the physician trying to enter the patient's world, seeing the illness through the patient's eyes

(Levenstein, McCracken, McWhinney, Stewart and Brown, 1986). The physician's agenda is defined as the explanation of the patient's illness in terms of taxonomy of disease, whereas the patient's agenda is defined in terms of expectations, feelings and fears.

For these studies (Papers I and II), the definition of the patient's agenda was expanded to include structures of illness meaning, referring to the participants' interpretations of the contextual meaning of illness and expressions of distress. The presentation of the later studies exploring patients restructuring of illness meaning (Papers III and IV) and the study exploring caregiver's experiences and meanings (Paper V) were inspired by the perspective of clinical care as a transaction of meanings. Good and Good (1980) emphasise that healing can be viewed as a transaction across meaning systems - popular, religious, folk, professional - that results in the construction of culturally specific illness realities and in therapeutic efforts to transform those realities. The EM model originally inspired the research path taken in this thesis. The research process has included a critique of, and movement back and forth in relation to, the EM model. This will be discussed further under the headings Procedure, Results, Discussion and in Papers I-IV.

### **The sense of coherence concept**

In the process of analysing and making sense of data collected for Studies I – IV attention was given to the concept of sense of coherence. The concept of sense of coherence (SOC) was developed by the sociologist Antonovsky (1988, 1993) in order to understand how people successfully cope with stress. In his book, "Unraveling the Mystery of Health" (1988, p. xii), Antonovsky formulates the salutogenetic question about why people are located towards the positive end of the health /disease continuum, or why they move towards this end, whatever their location at any given time? The answer Antonovsky developed was the cognitive *sense of coherence concept* (SOC). Antonovsky proposed that by making sense of countless stressors people are able, over time, to generate a strong sense of coherence. Antonovsky (1988, p.19) defines SOC as follows: "a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving 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 the stimuli; and (3) these demands are challenges, worthy of investment and engagement."

Antonovsky gives the SOC concept (1988, pp. 16-19) three core components, comprehensibility, manageability, and meaningfulness. *Comprehensibility*, refers to the extent to which one perceives the stimuli that confront one, deriving from the internal and external environments, as making cognitive sense, as information that is ordered, consistent, structured, and clear, rather than as noise-chaotic, disordered, random, accidental, inexplicable. The person high on the sense of comprehensibility expects that stimuli he or she will encounter in the future will be predictable or, at the very least, when they do come as surprises, that they will be orderable and explicable. *Manageability*, refers to the extent to which one perceives that the resources at one's disposal are adequate to meet the demands posed by the stimuli that bombard one. Resources under one's own control or controlled by legitimate others. *Meaningfulness*, refers to the extent to which one feels that life makes sense emotionally, that at least some of the problems and demands posed by living are worth investing energy in, are worthy of commitment and engagement, are challenges that are "welcome" rather than burdens that one would much rather do without. The SOC concept will be further discussed in the presentation of results from the studies exploring restructuring of illness meaning, (Papers III-IV).

## AIMS OF THE STUDIES

The *general aim* of this thesis is to explore, understand, and describe how a group of Swedish-born women and a group of Turkish-born women gave meaning to their illness. The participants were in contact with local health care in a multicultural area in Western Stockholm. They had all been assessed as somatizing by their caregivers. The definition adopted for somatization is a tendency to experience and communicate psychological and social distress in the form of physical symptoms, and to seek medical help for them (Lipowski, 1987). All the Turkish-born participants had experience of immigration and all had a low socio-economic status. The Swedish-born participants had a mixed socio-economic status.

The thesis has the *additional aims* of exploring the participants' restructuring of meaning given to illness and of exploring caregivers' experiences of, and meanings given to, the encounter with patients using a bodily idiom for emotional distress in a multicultural milieu. How the caregivers imparted their professional agenda of illness meaning was also examined. The thesis consists of five qualitative explorative studies, four with individual interviews of patients and one with focus group interviews with caregivers. The studies have been carried out separately and results are reported in five papers (I–V). Methodological issues of conducting focus group research are addressed in one paper (VI). The aims of each explorative study (I-IV) are as follows to:

**I** Explore structures of illness meaning among eight Swedish-born women, assessed by their caregivers as somatizing, in contact with local health care services in Western Stockholm.

**II** Explore structures of illness meaning among ten Turkish-born women, assessed by their caregivers as somatizing, in contact with local health care services in Western Stockholm.

**III** Explore restructuring of illness meaning among ten Turkish-born women, assessed as somatizing, encountering caregivers imposing a message of a “psychological language” for understanding their distress.

**IV** Explore restructuring of illness meaning among eight Swedish-born women, assessed as somatizing, encountering caregivers imposing a message of a “psychological language” of understanding their distress.

**V** Explore caregivers’ experiences of, and meanings given to, encountering patients using a bodily idiom for emotional distress in a multicultural milieu and to explore how the caregivers imparted their professional agenda of illness meaning.

The aim of the paper discussing methodology is to:

**VI** Discuss focus group interviews as a research method in transcultural psychiatry.

## METHODS

*“Doing qualitative research is an intense experience.  
It enriches one’s life; it captures one’s soul and intellect.”*

Morse and Field (1995, p. 1)

The studies in this thesis were conducted using qualitative methods. Individual interviews and a grounded theory approach were used in Studies I – IV. Study V used focus group interviews, content analysis and a grounded theory approach. Before presenting the methodology and procedure for each study I would like to make some general comments on the relevancy of qualitative methods for the studies in question. A more detailed presentation of the methodological framework of the studies will be given after some initial comments. This will be followed by a discussion of validity in qualitative research and ethics. The general comments on methodological framework will be followed by a presentation of methods and of the procedure used in each study.

### **Methodological framework of the studies**

Qualitative research methods have their roots in anthropology and sociology (Bogdan and Knopp Biklen, 1992). Focus group research has its roots in marketing research (Kreuger and Casey, 2000) and later in social science and public health research. Qualitative research is an umbrella term describing several research methods, approaches and diverse research paradigms (Guba & Lincoln, 1994). Guba and Lincoln (1994) suggest that qualitative research could be used with any research paradigm, with paradigm being defined as the basic belief system or worldview that guides the investigator. Qualitative research is contextual and subjective as opposed to generalisable and objective (Whittemore, Chase and Mandle, 2001). Qualitative methods have some common features; the natural setting is the direct source of data and the researcher the key instrument, they are descriptive and concerned with process, data are analysed inductively<sup>10</sup> and “meanings” are of essential concern (Bogdan and Knopp Biklen, 1992, pp. 29-30). Pope and Mays (2000) point to four major theoretical

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<sup>10</sup> Morse and Field (1995) define Inductive Theory: variables, concepts, constructs, and hypothesis are derived from relationships observed during the process of coding data. Thus, theory is constructed to explain the observed relationships as they emerge from data. This is in contrast to deductive theory. Morse and Field (1995) define Deductive Theory: variables, concepts, constructs, and hypotheses are derived from previous research. Relationships are tested during the research process. Theory is used to guide data collection and analysis.

perspectives with reference to having informed qualitative methods, (ethnography, symbolic interactionism, ethnomethodology and phenomenology) and with various theoretical stances frequently presented as clear cut, although in practice the contrast is often less apparent.

Qualitative research methods may be used to complement quantitative research, such as in the creation of survey questionnaires, the validating of results and reinterpretation of poorly understood data. Qualitative methods are also used independently (Pope and Mays, 2000). They are suggested to be particularly useful when describing phenomena from an emic<sup>11</sup> perspective (Morse and Field, 1995). Maxwell (1996, pp. 17-21) points to five particular research purposes for which qualitative research methods are especially suited: 1. understanding participants' meaning, 2. understanding the particular context within which the participants act, 3. identifying unanticipated phenomena and influences, and generating new grounded theories about the latter, 4. understanding the process by which events and actions take place, and 5. developing causal explanations. Furthermore, Maxwell states that the distinctive characteristic of hypotheses in qualitative research is that they are generally formulated after the research has started, grounded in data, and developed and tested in interaction with it.

Qualitative research methods deserve to be an essential component of health and health service research (Pope and Mays, 1995). Qualitative research approaches have opened up new ways for gaining knowledge about, and insights into, the complex interactions between mental health care and cultural groups and individuals, and may also uncover social processes in organisations. To this can be added other purposes such as local health promotion (Bloor, 1998). Through their contextualised character the methods are potentially powerful in discussion, advocacy and the influencing of local health care policy, as well as for the development of health organisations and the argument for change. It is suggested that the capacity of qualitative research for rich description enables practitioners to imaginatively juxtapose their own everyday practices with research descriptions (Bloor, 1998). Reviewing measuring of trauma and health status in refugees, Hollifield et al. (2002) propose that combining qualitative and

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<sup>11</sup> Canino et al. (1997, p. 166) define the 'emic' perspective as involving the evaluation of studied phenomena from within the culture and its context in an attempt to explicate the phenomena's significance and interrelationship with other intra-cultural elements 'from the inside'. This is done with the aim of characterising the internal logic of a culture, and its singularity, and is considered to be a necessary step prior to any valid cross-cultural analysis. This, in contrast to the 'etic' perspective, is fundamentally comparative, directed at eliciting overarching categories of phenomena out of local specifics. Its goal is to identify and compare equivalent phenomena across different cultural contexts.

quantitative methods may create measures that are valid in representing the experiences of the refugees, and that qualitative techniques allow for the development of culturally informed quantitative measures.

#### *Design and research question*

Design in qualitative research is an interactive process that involves moving back and forth between the different components of the design, and assessing the implications of purpose, theory, research questions, methods, conceptual context and threats to validity (Maxwell, 1996). In qualitative studies the research question is at the heart of the research and linked to the other components of design. The research question is often the point of departure (1996) and is changed or modified during data analysis according to the new understanding of the phenomena being studied. The research question states what the researcher wants to learn from the study (Maxwell, 1996). Strauss and Corbin (1990, p. 38) state: “The research question in a grounded theory study is a statement that identifies the phenomena to be studied.”

#### *Collecting data via interviews*

In this thesis, interviews, both individual and group, have been the major source of data collection. The purpose of the qualitative research interview is to understand themes from the participants’ everyday experience of the world from their own perspective (Kvale, 1996). In Studies I-IV data were collected via individual interviews. Collecting data through interviewing is an active and interactive process whereby knowledge evolves through a dialogue. Kvale (1996) points to the importance of recognising and applying the knowledge gained from interaction and to the interviewer using him/herself as an instrument. Holstein and Gubrium (1998, p. 113) claim that narratives are “all constructed *in situ*, as a product of the talk between interview participants” and that interviewing is an occasion for producing knowledge itself. They suggest that in interviews both parties are active and say, (p. 114) “Respondents are not so much repositories of knowledge – treasuries of information awaiting excavation, so to speak – as they are constructors of knowledge in collaboration with interviews. Participation in an interview involves meaning-making work”.

Regarding the construction of illness narratives, Hydén (1997) points to the decisive role of situational factors and that we continually produce new narratives in new contexts. Hydén (1997, p. 52) says: “Thus, it seems all the more evident that it is not a

question of *the* narrative, but rather of different possible narratives which are determined by situational factors, particularly by the interaction between narrator and listener.” Good (1994, p. 30) describes just how interactive and formative an interview situation may be and writes: “There are moments when interviewing a person in pain is indeed like witnessing the birth of language, as that person struggles to put into words an experience that resists language, a primal experience of the body that is at once ultimately real and ultimately indescribable, a force that so shapes the world that sufferers often describe themselves as inhabiting a world that others can never know.”

Group interviewing was the source of data in Study V. Morgan (1996, p. 130) defines focus groups as a “research technique that collects data through group interaction on topics determined by the researcher”. Group interviewing capitalises on communication between research participants in order to generate data (Kitzinger, 2000). Focus group research (FGR) is considered to be culturally sensitive and useful in studying different uses of health services, cultural values and work place cultures (Kitzinger, 2000). FGR is often used in combination with other methods, quantitative as well as qualitative. As a free-standing method, Bloor et al. (2001) regard focus groups as central in studies concerned with group norms, the group meanings that underpin those norms, and the group process whereby those meanings are constructed. Kitzinger (2000) proposes that focus group interviewing makes it possible for the researcher to gain access to communications that people use in day-to day interactions, and to highlight subcultural and cultural values and norms. Focus group interviewing includes two roles, with one moderator guiding the interview, and one observer. Both are recommended to have experience and knowledge of group dynamics (Lindencrona, Johansson Blight, and Ekblad, 2002). See Paper VI for a further discussion on focus group interviews, culture and psychiatry.

### *Sampling*

The purpose of sampling in qualitative methods is to identify specific groups of people who either possess characteristics, or live in circumstances, relevant to the social phenomena being studied. Sampling is often systematic and non-probabilistic and informants are identified because they enable exploration relevant to the research (Pope and Mays, 1995). Sample sizes are typically small, subjects being initially selected because they can illuminate the phenomena being studied. The continued selection of subjects is related to the findings that emerge in the course of the study (Sandelowski,

1986). One specific way of non-probabilistic sampling is theoretical sampling. This is a part of grounded theory procedure.

Theoretical sampling is defined as “sampling on the basis of concepts that have proven theoretical relevance to the evolving theory” (Strauss and Corbin, 1990, p. 176). Sampling is guided by questions and comparisons during analysis, the sampling procedure being related to the level of analysis (Strauss and Corbin, 1990). The relation between sampling and theory construction is interactive and theoretically led (Pope and Mays, 1995). Strauss and Corbin (1990) use the concept “theoretical saturation”. They define the latter as: “(1) no new or relevant data seem to emerge regarding a category (2) the category development is dense, insofar as all of the paradigm elements are accounted for, along with variation and process (3) the relationship between categories are well established and validated” (1990, p.188).

In discussing sampling in focus group research, Bloor et al. (2001) suggest that in order to obtain access to group norms and understandings there are advantages in recruiting participants from pre-existing groups. They also suggest that over-disclosure may be a problem and can result in the inclusion of sub-groups that have an inhibiting effect. Fern (2001) is of the opinion that the groups have to be homogenous regarding the individual characteristics that cause the shared perspective under investigation. Kitzinger and Barbour (1999) point to the importance of a flexible approach to sampling and the need to make an effort to consider voices which might not be heard. For a further discussion of this topic see Paper VI.

### *Data analysis and grounded theory*

Data from all explorative studies in this thesis have been analysed with a grounded theory approach. This means that the steps of grounded theory were followed, although with some modifications. For Study V, using focus group interviews, the analysis started with a content analysis followed by an inductive analysis. Grounded theory (GT) is a general methodology for developing theory<sup>12</sup> that is grounded in data systematically

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<sup>12</sup> Morse and Field (1995, p. 4) define theory, and the role of theory, for qualitative research as: “a systematic explanation of an event in which constructs and concepts are identified and relationships are proposed or predictions made. Basically, a theory is a hunch, a guess, a speculation, or idea that may explain reality. Theories guide investigation both in qualitative and quantitative research, but generally provide guidance at different stages in the research process. In qualitative research, inductive research, the researcher examines the data for patterns and relationships and then develops and tests hypotheses to generate theory or uses developed theories to explain data. Quantitative researchers, on the other hand, work deductively by testing developed theory.”

gathered and analysed. The theory evolves in a continuous interplay between analysis and data collection. Analysing and describing different methods for qualitative analysis, Titscher et al. (2001) suggests that GT always tries to conceptualise and categorise on the basis of text data and that the focus is on exploration and the generation of hypothesis. GT was initially presented by Glaser and Strauss in “The Discovery of Grounded Theory” (Strauss and Corbin, 1994). Tischer et al. (2000) suggests that one of the GT’s roots is American pragmatism. Grounded theory is an action/interactional-oriented method of theory building with a continuous interplay between proposing and checking. The analytic procedures are designed to: “(1) Build rather than only test theory. (2) Give the research process the rigour necessary to make the theory ‘good’ science. (3) Help the analyst to break through the biases and assumptions brought to, and that can develop during, the research process. (4) Provide the grounding, build the density, and develop the sensitivity and integration needed to generate a rich tightly woven, explanatory theory that closely approximates the reality it presents” (Strauss and Corbin, 1990, p. 57).

The central process by which theories are built from data is coding, carried out using a central technique of asking questions of the data and continuously making comparisons (Strauss and Corbin 1990). Coding is conceptualised in three major types: (a) open coding; (b) axial coding; and (c) selective coding. *Open coding* is defined as the process of breaking down, examining, comparing, conceptualising, and categorising data. This is the first step in the procedure of interpreting data. During this process comparisons are made and questions asked. *Axial coding* refers to a set of procedures whereby data are combined in new ways. This is done by making connections between categories and subcategories, i.e. combining data in a relational form. Strauss and Corbin describe open and axial coding as distinct analytic procedures with the researcher alternating between the two modes. *Selective coding* refers to the process of selecting the core category, systematically relating it to other categories, validating relationships, and filling in categories that need further refinement and development. The importance of finding a core category is emphasised and defined as the central phenomena around which all the other categories are integrated.

#### *Analysing data from focus groups*

There are problems and challenges connected with analysing data collected by focus group interviewing. Focus group research (FGR) raises some unique issues as data are

constructed in the interaction between participants. The data collected in interviews can thus be very complex and encompass a great degree of variability. Obtaining complex and varied data is one advantage with the method, but makes analysis difficult and problematic. The researcher is faced with the task of synthesising many diverse points of view and experiences into meaningful conclusions. Frankland and Bloor (1999) point out that current textbooks are often more concerned with procedure than analysis and that little attention has been given to techniques of analysis, and that this is clearly unsatisfactory. Bloor et al. (2001) suggest a first step in processing transcribed text from focus groups, i.e. to index data in order to make them manageable for interpretation, the aim of indexing being to bring together all extracts of data that are pertinent to content. See Paper VI for a further discussion about the analysis of data from focus group interviews.

### *Transcription*

The first step in analysing qualitative data from tape-recorded interviews is that of transcription. In these studies all the individual and focus group interviews – apart from two individual interviews - were tape-recorded. On one occasion a participant did not want the interview to be tape-recorded. The other occasion was when I, by mistake, did not switch on the tape-recorder. The interviews have been transcribed verbatim, 69 of them by secretaries and 7 by myself. After transcription I subjected them all to a careful scrutiny. The transcription process involves the transformation of the object of duplication into another form that is only partially representative, but not isomorphic with it. “Like the photograph, the transcript captures something, but not everything `out there’” (Sandelowski, 1994, p. 312).

### **Validity in qualitative research**

The difficulty of establishing validity criteria in qualitative research and the need for validity standards to incorporate rigour and subjectivity as well as creativity into the scientific process are topical areas of discussion (Whittemore, Chase and Mandle, 2001). Kvale (1996) suggests that traditional concepts of verification of knowledge have to be reconceptualised into relevant forms for interview research. For Kvale (1996), the concept of validity means quality of craftsmanship and includes communication about, and pragmatic effects of, knowledge. He suggests that validity concerns not only the methods used but also the person of the researcher, including his or her moral integrity.

The use of the term validity has been questioned with regard to qualitative research. Whittemore, Chase and Mandle (2001) propose, however, that validity is an accurate term offering immediate recognition and understanding in the scientific community.

Guba and Lincoln (1989) claim that for constructivist<sup>13</sup> inquiry the traditional criteria of internal validity, external validity, reliability, and objectivity are not workable for evaluating the goodness of inquiries. They consider the criteria to be rooted in the assumptions of the research paradigm for quantitative research and state that the conventional criteria can not apply *in any sense* to constructivist studies. Guba and Lincoln have suggested that there are three different approaches to considering the quality of goodness for evaluation in constructivist inquiry: the trustworthiness criteria, the nature of the hermeneutic process itself and the authenticity criteria. Strategies for protecting the validity of findings in the studies of this thesis will be discussed under the heading Procedure.

#### *Putting a name to quality*

Guba and Lincoln (1989) have developed a set of criteria parallel to the conventional ones, staying as close as possible to the conventional criteria of quality. These translated criteria are considered by Whittemore, Chase, and Mandle (2001) to be the gold standard in the literature. The *trustworthiness* criteria are intended to parallel the conventional rigour criteria. The *credibility* criterion is parallel to internal validity in that the idea of isomorphism between findings and objective reality is replaced by isomorphism between constructed realities of the respondent and the reconstructions attributed to them. Instead of focusing on a presumed real reality the focus has moved to establish a match between the constructed realities of the respondents and those realities represented by the evaluator and attributed to respondents. Guba and Lincoln suggest several techniques for increasing the probability of verifying isomorphism, such as: prolonged engagement, persistent observation, peer debriefing, negative case analysis, progressive subjectivity, and member checks.

The *transferability* criterion is parallel to external validity or generalisability. External validity is replaced by an empirical process for checking the degree of similarity between sending and receiving context. Also, the burden of proof is not on the inquirer

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<sup>13</sup> Guba and Lincoln (1994) commit themselves to the paradigm of constructivism (earlier named naturalistic inquiry), considering ontology as relativist – with local and specific constructed realities, and epistemology as knowledge created in interaction between investigator and respondents.

but on the recipient. The burden of proof for claimed generalisability is on the inquirer, while the burden of proof for claimed transferability is on the recipient. The major technique for establishing the degree of transferability is “thick description”<sup>14</sup>.

The *dependability* criterion is parallel to the conventional criterion of reliability, and concerns the stability of the data over time. Guba and Lincoln suggest that methodological changes and shift of constructions are hallmarks of mature and successful inquiry, but that they need to be tracked and trackable. Techniques for documenting the logic process and method decisions are designated “dependability audit”.

The *confirmability* criterion is parallel to objectivity. It is concerned with assuring that data, interpretations, and outcomes of inquiries are rooted in the context. This is so that data can be tracked to their source, and that the logic used to assemble the interpretations into structurally coherent and corroborating wholes is both explicit and implicit. Guba and Lincoln designate techniques for confirming the data and interpretations of a given study as the “confirmability audit”, and stipulate that it is to be carried out with the “dependability audit”. Another way of judging quality according to Guba and Lincoln is to look within the nature of the hermeneutic process itself. They consider that in the emerging joint collaborative construction of data inputs, analysis, revision and feedback, that there are very few opportunities for error to go undetected and/or unchallenged. *The authenticity criteria*, Guba and Lincoln suggest, spring directly from constructivism’s own basic assumptions and do not focus on methodology but on outcome, product and negotiation including; fairness<sup>15</sup>, ontological authenticity<sup>16</sup>, educative authenticity<sup>17</sup>, catalytic authenticity and tactical authenticity<sup>18</sup>.

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<sup>14</sup> Thick description is a concept originally referred to by the anthropologist Clifford Geertz (1973). In their definition, Morse and Field (1995, p. 243) write: “Thick description presents more than a superficial commentary on the ongoing activities. Thick description details the affect, relationships, contexts, and backgrounds and interprets the tones of the voices, the feelings, and the meaning of the situation.” Geertz (1973, p. 16) says: “It is not against a body of interpreted data, radically thinned descriptions, that we measure the cogency of our explications, but against the power of the scientific imagination to bring us into touch with the lives of strangers.”

<sup>15</sup> *Fairness* refers to the extent to which different constructions and their underlying value structures are solicited, honoured and presented since inquiry is value-bound and value-situated. It is achieved by the use of techniques exploring values of conflict and by open negotiation. Fairness requires a constant use of a member-check process.

<sup>16</sup> *Ontological authenticity* refers to the extent to which individual respondents’ own emic constructions are improved, matured, expanded, and elaborated, in that they possess more information and have become more sophisticated in their use.

<sup>17</sup> *Educative authenticity* refers to the enhancement of the individual respondents’ understanding and appreciation of the construction of others.

<sup>18</sup> *Catalytic authenticity* is defined as the extent to which action is stimulated and facilitated, and *tactical authenticity* refers to empowerment to act.

## **Ethics**

Ethical approval for the studies was given by the local research ethics committee Nord KS. For Studies I –II Dnr 96-336 and for Studies III-V Dnr 00-366. Ethical recommendations for biomedical research involving human subjects have been stipulated by the World Medical Association's Declaration of Helsinki (2000). As basic moral values for medical ethics, and to summarise the norms of medical ethics in different cultures, religious and political traditions, four ethical concepts have been established; *autonomy, non-maleficence, beneficence, and justice*, according to the Appleton consensus (Dahlström, 1989). Due to the methodological character of qualitative research, ethical concerns are involved in every aspect of design (Maxwell, 1996). It has been suggested that the procedures of qualitative research methods do not generally place participants at risk but generate specific ethical problems. Research participants may be exposed to data collection that is both intrusive and invasive of sensitive experiences, and ethical considerations arise and are acknowledged in unique and subtle ways (Robley, 1995; Usher and Holmes, 1997).

Since the Nuremberg trials, informed consent has become a cornerstone of ethical research for protecting the patient (Lynöe, 1999; Osborn, 1999). Several authors have examined the need for continuous re-negotiation of informed consent that takes into account the unforeseeable directions in which the subject is drawn during the qualitative research process (Ramos, 1989; Holloway and Wheeler, 1995; Usher and Holmes, 1997). Qualitative research methods may involve ethical conflicts between using people to further knowledge and safeguarding the individual (Ramos, 1989; Robley, 1995). According to Kvale (1996), interviewing in qualitative research involves a delicate balance between cognitive knowledge seeking and the ethical aspects of emotional human interaction. The World Medical Association's Declaration of Helsinki (2000) gives very clear guidelines about cases in which there is a conflict of interest between using individuals for further knowledge production and safeguarding individuals. It states that in human research, the interests of science and society should never take precedence over considerations related to the well being of the subject.

Respecting the autonomy and integrity of participants, as well as their well being, has been an important issue throughout the research process of these studies. Beauchamp (1999) defines respect for autonomy as respecting the decision-making capacities of autonomous persons. In a thesis exploring the meaning of the concept of integrity, Andersson (1996) relates patient's integrity to a personal sphere, with values and wishes

related to the boundaries of the personal sphere. In the present studies, ethical concerns have been addressed by regularly re-negotiating the informed consent and checking on participants' understanding of the research situation. During the research process, it became evident that in order to respect the autonomy and integrity of participants, attention also had to be paid to their views on ethical issues as these may be given different meanings (Bäärnhielm and Ekblad, 2002). Elliot (1999) has emphasised the importance, for cross-cultural research, of understanding the background of those to whom ethical principles are to make sense. For a further discussion of ethics and qualitative research see Bäärnhielm and Ekblad (2002).

## **Procedure**

### *Sampling and samples*

#### Study I, sampling and sample

In Study I sampling was made by referral from clinicians in primary, psychiatric and occupational care. For a time schedule of the study see page 19. The sample in Study I comprised eight participants. Participation was voluntary. The inclusion criteria were: Swedish-born female patients assessed as somatizing (according to Lipowsky's definition, see page 17), being in contact with primary or psychiatric care in the local area (Spånga), in the age range 25-55 years. Symptoms were required to have been present for at least 6 months. It was difficult to get the clinicians to recruit Swedish-born participants, because few Swedish-born patients were in contact with the participating facilities in the suburbs of Tensta and Rinkeby. Clinicians at the primary care unit serving an area with a majority of Swedish-born inhabitants considered somatization to be rare among Swedish-born women. Clinicians at a nearby psychiatric and an occupational unit, situated close to Spånga, were informed about the study and Swedish-born participants were recruited immediately. Sampling continued until data from new interviews started to "fit" in with the emerging categories, pattern and theoretical construction as well as show variation.

Six of the eight participants were referred from local psychiatric services, one from primary care and one from occupational care. Their ages ranged from 30 to 55 with a mean age of 47 years at the start of the study. Four were married and four were unmarried or divorced. Three had children under 18 years of age. Four had an education of less than 11 years and four had a school education of 12 years, with a mean of 8.2

years. Four had a higher education. Three were working full-time, two combining work and sick leave, and three had only some form of sickness benefit.

Diagnostic interviews were conducted by myself, using the structured interview manual of SCID (SCID-RV, 1996) for Axis I in order to confirm the psychiatric assessment of the clinicians according to DSM-IV (APA, 1994). The diagnostic interviews were performed after two to three explorative interviews. All participants had at least one psychiatric diagnosis according to DSM IV Axis I. Several participants had more than one diagnosis. The following diagnoses were established: Major Depressive Disorder, Single episode 296.22 one, Major Depressive Disorder, Recurrent 296.32 two, Dysthymic disorder 300.4 two, Panic Disorder Without Agoraphobia 300.01 four, Generalized Anxiety Disorder 300.02 one, Somatization Disorder 300.81 two, Pain Disorder Associated With Psychological Factors, Chronic 307.80 one.

Primary care medical records were collected with the participant's approval at the time of the interviews. Records varied in quality and style and covered different time periods. The diagnoses in the primary care medical records were often formulated in general terms and did not refer to any specific diagnostic system. According to medical records, pain was a prominent symptom for eight out of eight. The participants had received the following diagnoses for pain: fibromyalgia two, migraine one, myalgia two, whiplash injury one. When a somatic diagnosis was given for pain, a check was made, with the approval of the participants, to confirm the selection criteria. Four participants had received psychiatric diagnoses. Psychosocial problems were registered in five cases and in four cases the patient's opinion about the symptoms had been documented.

### Study II, sampling and sample

In Study II sampling was made by referral from clinicians in primary and psychiatric care in the local area Spånga. See page 19 for a time schedule of the study. The sample of Study II comprised ten participants. Participation was voluntarily. Six out of ten participants were referred from the local psychiatric services and four from primary health care in Spånga. The inclusion criteria were: Turkish-born female patients assessed as somatizing (according to Lipowski's definition, see p. 17), being in contact with primary or psychiatric care in the local area, in the age range 25-55 years. Symptoms had to have been present for at least 6 months. The speed of referral of Turkish-born participants was regulated by my reminding the clinicians about the study. Participants' ages ranged from 31 to 48 with a mean age of 35 years at the start of the

study. Six originated from the Kulu area (see Introduction, pp. 22-23) and four from other parts of Turkey, small towns or rural areas. Concerning ethnical affiliation: eight were Turkish, one Kurdish and one Assyrian. Five were Swedish citizens and five were Turkish citizens. The background of immigration was diverse and included, work, marriage, following the family, refugee status. The duration of their stay in Sweden ranged from 4 to 29 years with a mean duration of 19 years. All had children under 18 years of age. Seven participants were married and three divorced. All had a low socio-economic status. The participants had a school education of between 0-12 years with a mean of 6.5 years. No one had a higher education. Three were working, four were receiving some form of sickness benefit, one was on social security and two were without own income. All participants intended to stay in Sweden, although one of them wanted to return to Turkey. Eight of the ten evaluated their language skills in Swedish as being good to fluent and two as having difficulties with the Swedish language.

I conducted diagnostic interviews following the same procedure as in Study I. For one Turkish-born participant, who showed difficulty understanding the questions, the SCID interview was abandoned in favour of an ordinary psychiatric assessment. All participants had psychiatric diagnoses according to the SCID interviews. Several participants had more than one diagnosis. The following diagnoses were established: Major Depressive Disorder, Single Episode 296.22 two, Major Depressive Disorder, Recurrent 296.32 one, Dysthymic Disorder 300.4 five, Panic Disorder With Agoraphobia 300.21 seven, Generalized Anxiety Disorder 300.02 one, Somatization Disorder 300.81 one, Pain Disorder Associated With Psychological Factors, Chronic 307.80 four.

Primary care medical records were collected with the participants' approval. All had been in contact with primary care. Records varied in both quality and style, and covered different time periods as well as a wide range of somatic symptoms. Various assessments had been made. According to the medical records, nine out of ten had pain. The participants had received the following diagnoses for pain: myositis one, myalgia four, fibromyalgia two, lumbago sciatica two, psychosomatic pain one, chronic pain syndrome one. Five had received psychiatric diagnoses. The diagnoses of the primary medical records were often formulated in general terms and did not refer to any specific diagnostic system. In two cases the patient's opinion about symptoms had been registered in the medical records. Alternative medicine or folk cures were never discussed according to the medical records. When a somatic diagnosis was given for

tain a check was made, with the approval of the participants, to confirm the selection criteria.

#### Study III, sampling and sample

Sampling for Study III was carried out by asking the Turkish-born participants from Study II to voluntarily participate in new interviews. Study III was conducted in spring 2001, two years after the completion of Study II. For a time schedule see page 19. Eight of the original ten participants from Study II participated. One of the original participants did not wish to participate and one could not be reached.

#### Study IV, sampling and sample

Sampling for Study IV was carried out by asking the Swedish-born participants from Study I to voluntarily participate in new interviews. The study was performed in spring 2001, two years after the completion of Study I. For a time schedule see page 19. Seven of the original eight participants from Study I participated. One of the original participants could not be reached.

#### Study V, sampling and sample

Sampling was conducted by asking caregivers working at settings in Spånga to participate. Participation was voluntary. This sampling strategy was chosen as the purpose was to gain access to the general experiences of encountering and imparting a professional agenda and not to be limited to the experiences of the patients that had participated in the individual interviews. Seven focus group interviews were conducted with caregivers in the local area. Two focus group interviews were carried out at the local psychiatric unit, one in the primary care setting serving the Swedish-born majority (Spånga), and two at each of the primary care settings in the multicultural area (Tensta). The primary care setting in Rinkeby did not participate because of lack of time. The psychiatric unit served all three primary care settings. For a time schedule see page 19.

The sample consisted of 35 caregivers. Caregivers' clinical experiences were in the context of a collaborative work situation between different professionals. In order to reflect this situation it was decided to include all the different professional categories involved in the clinical encounters. The study participants belonged to the following professional categories: secretary 2, medical social worker 2, mental health nursing auxiliary 3, assistant nurse 4, psychologist 5, physician 7, and nurse 12. There were 31

females and 4 males. The ethnical background of participants was very diverse and one third had their own immigrant background. Many had long clinical experience from the local area. Several caregivers had experience of working abroad. Some had worked in their countries of origin; others had worked in Swedish aid projects.

### *Data collection*

#### Studies I and II, data collection

Data collection took place during the three year period, January 1997 to December 1999 (time schedule see page 19). The study with the Turkish-born participants (Paper II) started shortly before, and ended somewhat earlier, than the study with the Swedish-born participants (Paper I). Participation was voluntarily, as mentioned above, and informed consent given orally. The different steps in the studies were performed in parallel but with a focus on data collection at the start and documentation at the end. The interviews were preceded by written and oral information, either by telephone or personal encounter. My role of researcher was clarified. Participants were informed about my professional affiliation, i.e. of being a physician and a psychiatrist.

In a first session, two to three interviews were conducted with each participant. Interviews lasted 60-120 minutes. One year after the first interview sessions, follow-up interviews were carried out. Follow-up interviews were frequently shorter than the first sessions and were used for feedback, questioning, and checking the analysis process as well as for verifying the theoretical construction. All planned interviews were carried out, except for two follow-up interviews in the Turkish born-group (Paper II) - one woman could not be found and one did not want to participate. All the Swedish-born participants participated in the follow up interviews. Together with follow-up interviews, 25 explorative interviews were conducted with eight Swedish-born participants (Paper I) and 29 with ten Turkish-born participants (Paper II). The interviews were tape-recorded. The first interview sessions started with broad questions clarifying the domain of the study. The second interview often had a more probing character. An interview guide was created after an analysis of the first pilot interviews (see Appendix 1). The interviews were tape-recorded, open-ended, and interactive, and the initial question was often, "Tell me about the condition of your health?" Participants were encouraged to respond in narrative form. Probe questions were used to elicit information concerning: help-seeking, family and social network, illness attribution, folk traditions, alternative medicine, recovery, mental health and ways of seeking knowledge about illness.

An interpreter was used with four Turkish-born participants in all interviews. For one participant an interpreter was used in some interviews, and for five of the interviewees only Swedish was used. With the Turkish-born participants, sixteen interviews were conducted in Swedish and thirteen through a Turkish interpreter. Two main interpreters, qualified in medical interpretation and with long experience of psychiatric care, interpreted in most interviews. One participant wanted an interpreter that she had used earlier. Prior to the interviews the Turkish interpreters were informed about the aim of the study, and instructed to interpret as close as possible to translation<sup>19</sup>, as well as to intervene whenever linguistic difficulties or problems arose. Time was allocated after the interviews for discussing translation and interpretation issues that had arisen during the interviews.

The participants chose the location for the interviews. Five of the Swedish-born participants chose to be interviewed in a psychiatric setting, two at home, and one first in a psychiatric setting and then at home. Two of the Turkish-born participants chose to be interviewed in a psychiatric setting, one first in a psychiatric setting and then at home, two in a primary care setting, one first in a primary care setting and then at home, and four to have the interviews conducted at home. Time was spent socialising before and after the interviews and a tea or coffee break was often taken during the interview. During some interviews, persons from the participant's social network were present and took part, e.g. children, mother, mother in-law, husband, or friends. Telephone calls or social responsibilities sometimes interrupted the interviews. In the interview situations, I became acquainted with the daily lives of the participants. When I reflect upon those interviews, I consider that they were conducted in an atmosphere characterised by a warm emotional response from the participants. My interest in listening to their personal story, experiences and ideas was appreciated. I think that these factors contributed to creating the trust necessary to make the interviews meaningful.

When talking about sensitive topics, some participants, on some occasions, asked to switch off the tape recorder. Data from these parts of the interviews have not been used for further analysis in accord with participants' wishes. On the other hand, important and meaningful data, collected during the SCID interviews, which were not tape recorded, have been used in the further analysis process and participants informed of this. On one

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<sup>19</sup> Translation refers to the ability to exchange words from one language for those of another language while retaining the same meaning, and interpretation refers to the transmission of connotative (associated meaning or emotional colouring) as well as denotative (specific meaning of a word) meaning (Westermeyer, 1990; Westermeyer and Janca, 1997).

occasion, a follow-up interview was stopped on my initiative because of the poor condition of the participant's health. The participant was positive to having the interview stopped.

After most interview sessions, ethnographic field notes were written. An example of a quite typical field note is given below. This is a part of the field note from my first visit to interview the participant Mesude, a 33 year old women (Study II). Her name and all other names used in this thesis frame and in the Papers are pseudonyms. The same pseudonyms have been retained throughout the various texts. Details have been changed where necessary in order to protect confidentiality.

Mesude meets me at the door. She has a crutch and walks with difficulty. She looks as if she is suffering a great deal. In the hall there is a large plastic mat. On one wall in the hall hangs a large tapestry of Mecca. We sit down in the dining room containing two sofas with light flowery covers. During the first part of the interview Mesude's right leg shivers. Her right arm lies on her lap as if it is paralysed. She is able to move it. Mesude points to a mattress on the floor and says that she usually sleeps there. Because of her back pain she can not sleep in a bed. Behind the mattress, there are several pillows. Along the long wall of the room stand white bookshelves with pictures of the children. On the opposite wall, above one of the sofas, hang two pictures with religious motives. Behind the sofa there is a large painting with a gold frame. There is Arabic text on it. Beside this there is another painting with Arabic text. Later in the interview Mesude says that she was given the painting with the gold frame by her mother. She was given it in order to make her healthy. She does not really believe in this but does not want to break her mother's heart.

..... The coffee table is laid with one thermos, two cups, and three plates with three buns on each. Mesude says that her mother has been there to help her. Her mother has left so that we will be able to talk on our own. Her sister has phoned and reminded her that her doctor is coming. She smiles at me and says that they think that I am her doctor. That they do not really understand. During the interview the telephone rings three times. Her brother phones and asks where his wife is. Her sister in-law phones and says that she is at home now. Her brother phones and asks about Mesude's health. ...

### Studies III and IV, data collection

Data collection and analyses were carried out in two steps for Studies III and IV. Data for the earlier Studies I and II were reanalysed. New data were collected via new interviews in spring 2001. For a time schedule, see page 19. Participants from Studies I and II were contacted and informed about the new studies. They were informed about the aim of the study, its procedure and told that participation was voluntary. Informed consent was given orally. Eight of the original ten Turkish-born participants participated in the new interviews exploring restructuring of illness meaning (Paper III), one did not want to participate and one could not be reached. Seven of the eight Swedish-born participants participated (Paper IV), one participant could not be reached. Prior to interviewing, time was allotted for disseminating information about the results of the preceding study.

In conducting the interviews, time and effort was spent in creating an atmosphere of openness and purpose in order to talk about the sensitive issue of making sense of, and dealing with, caregivers' proposed message of illness understanding. Participants were interviewed on one occasion only. Four of the Turkish-born participants were interviewed in Swedish and four with a Turkish interpreter (Paper III). Two different qualified Turkish-interpreters were used. The interpreters had participated in the preceding Study II. With the Turkish-born participants, eight new interviews about restructuring illness meaning were conducted for Study III. Six were made in the participants' home and two at the local psychiatric out patient unit. Seven new interviews about restructuring illness meaning were conducted with the Swedish-born participants. Three were carried out in the participants' home and four at clinical settings. The interviews in both studies lasted 60-90 minutes, often with a break for tea or coffee. All interviews in Studies III and IV, except one, were tape-recorded and transcribed verbatim. One participant, in Study III, did not wish the interview to be tape-recorded. For this interview, field notes were written after the interview. Interviews using a Turkish interpreter were transcribed in Swedish.

In Studies III and IV, participants were interviewed about: perceived health, treatment received, meaning given to caregivers' psychological message of illness understanding, psychiatric conceptualisation, integration of caregivers' message of illness understanding with previous understandings, the role of the social context for integration of medical information (see Appendix 2). Participants were encouraged to respond in a narrative form. The interviews were used to more closely examine aspects

that had been identified in the analysis process. The interviews focused on the same illness experiences as in the preceding interviews exploring illness meaning (Studies I and II). The current health situation was also reflected. In each study one of the participants found herself to have recovered since the first interview sessions of Studies I and II. The others reported that their distress had continued.

From earlier interview sessions, the participants were accustomed to responding in a narrative form. Questions about the meaning of caregivers' message and psychiatric treatment could not be posed too early in the interviews as they then received polite but meagre answers. When time was made available to talk about the present health situation and experiences from the clinical encounter, probing questions about the meaning given to the caregivers' message yielded rich responses, such as the relating of concrete situations and the meanings given to them.

#### Study V, data collection

Data collection took place in spring 2001. Before the start of the study, oral and written information (aim, background, procedure, voluntary participation and confidentiality) was given to the staff at each unit. Informed consent was given orally. Some professionals expressed fear and reluctance about the risk of intrusion in connection with being interviewed in groups. Time was given to discuss these worries and to inform those concerned about the methodology of focus group research. It was stressed that participation was voluntary. There were initial difficulties with organising times for the interviews in primary care. After the first interview session had been conducted it became easy to make appointments for the following interviews.

My scientific supervisor, Solvig Ekblad, and I carried out the focus group interviews together. Two persons were required, one as moderator and one as observer. SE had experience and training in performing focus group interviews (for a further discussion see Paper VI). Our roles shifted between sessions. After each interview session we discussed the content of the interviews and the interaction observed. Two of the interviews were conducted in the evening after the working day, four during working hours, and one at lunchtime. At three of the units, the interviews were performed in conference rooms and at one unit (in the multicultural area) in a narrow room that was a combination of kitchen, conference room, and workroom. The groups consisted of three to seven participants. Caregivers let us share broad spectra of experiences, practices, thoughts, and opinions in interaction with each other. The interviews were semi-

structured with the moderator following an interview guide (see Appendix 1 Paper V). The interview guide was constructed to facilitate the collection of experiences and meaning without preconceptions, but also for probing how patients' illness meaning and differences between patients and caregivers' illness realities were managed in the clinical encounter.

### *Research question and data analysis*

#### Studies I and II, research question and data analysis

Formulation of the research question and the data analysis process will be described here for Studies I and II. The analysis process included a constant "back and forth" loop between components such as design, purpose, theory, research question, method, and scientific rigour and verification of knowledge. Data collection, sampling and analysis were conducted parallel, and tightly interwoven, with each other. The same procedure was followed for the two studies. Data from the two studies were used for comparison in the analysis process. The studies were kept separate to make it possible to understand the groups within their own framework. The situation of having two sets of data was used as a resource in the inductive analytic process. The relation between theoretical frame and openness for discovery has been a part of the two studies.

The research question was changed during Studies I and II. The original aim of Studies I and II was to survey the participants' explanatory models of illness. The research question was based on a more or less clearly formulated pre-assumption of an expectation of a culturally shared coherent "belief-system" with a great emphasis on causal attribution, not yet explored but there for the researcher to explore and depict. Analysing the initial data it became clear that it would be necessary to change the research question. The initially direct questions posed about illness explanation, and causal connection elicited poor responses, such as no response, or that explanation was the task of the physician, or very scanty explanations of attribution. The participants were eager to recount their illness narratives, to tell of experiences and efforts in making sense of illness, and of the encounter with the health care services. They spoke also of trying other healing sources; the Turkish-born participants referred to medical care in Turkey and traditional healing, and the Swedish-born participants reported using alternative care. It seemed to be meaningful to start the interviews at the place in which the participants found themselves. The research question was reformulated to that of

exploring structures of illness meaning, referring to the interpretation of participants' contextual meaning of illness - in a situation of suffering and clinical encounter.

The first step of organising and analysing the data into categories was open coding whereby data was rigorously reviewed with regard to what it might tell us. Miles and Huberman (1994, p. 56) define codes as: "tags or labels for assigning units of meaning to the descriptive or inferential information compiled during a study. Codes are usually attached to 'chunks' of varying size, words, phrases, sentences, or whole paragraphs, connected or unconnected to a specific setting." Coffey and Atkinson (1996) suggest that coding should be thought of as essentially heuristic, providing ways of interacting with, and thinking about, the data and opening them up for analytic possibilities. Coffey and Atkinson (1996, p. 29) state "we are attaching codes as a way of identifying and reordering data, allowing the data to be thought about in new and different ways".

The first level of the analysis process was that of open coding according to the methodological steps of grounded theory. Coding was performed by scrutinising the text in chunks of varying sizes such as, words, expressions, lines, paragraphs and complete interviews. The situation of having two parallel studies with two sets of data enabled comparisons to be made and generated questions and new ideas about the data. Solvig Ekblad, my scientific supervisor, played an active role in the analysis process by studying the data, discussing coding and theoretical construction, and by posing new questions, and pointing to alternative ways of interpreting together with me. Coding was performed and organised using the software program QSR NUD\*IST rev 4 (N4).

The software program N4 has been developed for the support and management of qualitative data analysis projects. N4 was used for coding data, indexing, linking relations between categories, comparing, locating answers to questions, looking for key ideas, re-coding, re-organisation, testing and checking. It was also used for constructing hierarchies of the conceptual categorisations and for "playing around" with data to help create more abstract interpretations, conceptualisations etc. Using N4 was initially time-consuming but facilitated the process of re-thinking and re-organisation of data like, re-coding, re-labelling, indexing, and new ways of constructing and linking categories, comparisons, pattern-search and adding new questions along the lines of new understanding in the process of theory construction.

N4 was also used with the aim of making the path of theory construction accessible for others and for leaving trackable audits along the way. Using N4 is time-consuming but contributes to making the intellectual process of categorising and indexing explicit.

It also imposes rigour (Lewando-Hundt et al., 1995). One shortcoming with N4 is the limited capacity for textual display of the hierarchical construction of codes. N4 was also used for writing memoranda. Memoranda were used for recording ideas and thoughts associated with categorisations, linking relations, pattern-search, and documenting thoughts and tentative interpretations. They were used in the construction of theoretical outlines.

The second level of the analysis process, axial coding, entailed moving from open coding to interpretation and re-construction. Miles and Huberman (1994) describe coding as a process of creating increasingly more abstract categories, with inferential and explanatory codes pulling a lot of material together, thus permitting analysis. Discussing the inductive analytic process, Miles and Huberman (1994, p. 152) say, “This abstracted web of meaning is an achievement, not a given”. The data set of the studies was analysed for links and connections between different codes, for patterns<sup>20</sup>, and for relations between categories that could be put together to attain a new understanding. This was done by constantly referring back to the raw data for checking. The process of combining data was revised several times. Diverse blind alleys were tested. One of these was that I initially tried to make sense of data too quickly. I was guided by a revised pre-assumption to search for *the* meaning. This refers to some form of more or less distinct, alternative construction of meaning, like exotic ideas, alternative “belief system”, or causal explanation giving a clear and stable picture of participants’ perspectives. The assumptions did not fit with the data and I had to return to the initial data, which had to be reviewed for what it had to tell us, with all its ambiguity and complexity.

The third level of the analysis process was not focusing on selecting a single core category but on the construction of a theoretical understanding and formulation. This was carried out in interaction with the literature and the initial theoretical framework. Follow-up interviews were conducted after one year. These were used for feedback, questioning, and checking the analysis process as well as for verifying the theoretical construction. This form of member-check was made with the aim of verifying emerging results and for forming the theory into a collaborative construction.

These three levels of analysis were continually interwoven and proceeded with a back and forth movement between the different components, theoretical framework, and theoretical construction, checking and questioning. The two studies were like slow

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<sup>20</sup> Patterns refer to repeated relationships between properties and dimensions of categories (Strauss and Corbin, 1990).

spirals moving from an amount of raw data towards an interpretative construction of theory. The communication of the results of Studies I and II has focused on making a dense and contextualised interpretative construction of participants' illness meaning within their framework of interaction and active sense making.

#### Studies III and IV, research question and data analysis

Studies III and IV were carried out parallel and with the same design. The situation of having two parallel studies with two sets of data was again used for continuous comparisons and considering data. The research question of exploring re-structuring of illness meaning was not changed during the Studies. This time the research question was rooted in the findings from Studies I and II. Data collection and analyses for Studies III and IV were carried out in two steps. The first step was that of starting a secondary analysis of qualitative data collected for the preceding interview studies of exploring illness meaning, Studies I and II. The term secondary analysis refers to data being gathered in a previous study and subsequently reanalysed. The analysis can be made either by the original researcher or by another, and addresses new questions or looks at the same questions with different methods of analysis (Szabo and Strang, 1997). The secondary analysis, of the earlier collected interview data, focused on participants' process of restructuring illness meaning. Data were used to explore how participants had understood and introduced order and meaning into their caregivers' proffered message of a "psychological language" of understanding and treating their distress.

The second step in Studies III and IV consisted of new semi-structured interviews exploring restructuring illness meaning. Data from Studies III and IV were analysed inductively using a GT approach to construct an understanding of participants' meaning making from their frame, an emic perspective. Meaning here refers to the interpretation of participants' contextual understanding of: their caregivers' psychological and psychiatric agenda of understanding their distress, their clinical encounter, and psychiatric treatment received. The analysis included the same procedure as described for Studies I and II. The analysis included moving back and forth between the new interviews and the earlier data collected for Studies I and II. This meant that the two steps of the studies were closely interwoven. The several data sets from the same participants collected at three different times (the initial 1-3 interviews, the follow up interview made one year later in Studies I and II, and the new interview in Studies III-IV) were used for comparisons.

Codes, themes, categories and theory construction were continuously tested by in-depth discussions between the researcher and the scientific supervisor of the study, Solvig Ekblad. In analysing data from the first step, N4 was used and for the second step QSR NVivo 1.2 (Nvivo). Nvivo 1.2 is a more recent and more flexible program with an enhanced capacity for linking and analysing data. Grounded Theory methodology emphasises the importance of selecting a core category. Studies I and II have not focused on presenting a core category. Studies III and IV can be seen as collecting further data to continue the analysis from the preceding studies and formulating a core category. The core category was formulated in a broader sense than in a single term. Results of the analysis were formulated in interaction with reading the literature and considering the theoretical framework of the studies.

#### Study V, research question and data analysis

The original research question for Study V was formulated in terms of exploring caregivers' experiences and attitudes in encounters with patients using a bodily idiom for emotional distress in a multicultural milieu, and of examining how the caregivers imparted their professional agenda of illness meaning. During the research process, the research question was reformulated in terms of exploring experiences and meanings. This was done as the caregivers were letting us share a broad spectra of experiences, practices, thoughts, and opinions in interaction with each other in a much wider sense than covered by the term "attitudes".

In formulating the aims of the study, we (Solvig Ekblad and I) were inspired by the emerging findings from the parallel studies (III-IV) about the relevance of Antonovsky's (1988) SOC concept for the participating patients' process of restructuring illness meaning. This led to curiosity about the caregivers' experiences of the clinical encounter as well as the meanings they gave to it. We were also interested in their experiences of imparting their professional agenda of illness meaning to the patients. The interview guide covered the following areas: clinical experiences, imparting professional assessments, patients' response to professional assessments, wishes regarding clinical development, other issues (see Appendix 1 Paper V). Probe questions were added during the course of the interviews and the exploration process.

The data analysis started with the same procedure as used in Studies I-IV with open coding and later axial coding according to the methodological steps of grounded theory. This did not work. Data were too complex and interwoven. After re-reading interviews

and re-thinking the analysis we decided to proceed in two steps. Step one was a content analysis of data. In qualitative research the concept of content analysis has no homogeneous understanding as a single method (Titscher et al., 2000). In Study V the content analysis was made by descriptively indexing data related to content, and bringing together all data belonging to a particular topic. Data were organised into nine major domains of content. In step two, data from each of the nine domains were analysed inductively according to grounded theory. This way of analysing data in two steps worked. Using the software program Nvivo 1.2 technically facilitated indexing and analysing data.

### *Validity*

#### Studies I-IV, validity

Strategies for protecting validity will be described for Studies I –IV together as these were used in a similar way. In all the studies, the analysis process included continuous movement back and forth between different components of the design. This way of working meant a continuous verification of theory construction and a quality control throughout all the stages of knowledge production. Kvale (1996) points to the importance of meaning clarification during the interviews by testing hypotheses and interpretations. In all the studies the interviews were used for clarifying and testing emerging results. For Studies I and II, the later follow-up interviews could be used for probing and checking for understanding of earlier interviews.

My scientific supervisor, Solvig Ekblad, had an active role in the verification process. She assisted in Studies I to IV by reading transcribed interviews and discussing the analysis process. The software programs N4 and Nvivo 1.2 were initially used for practical reasons as qualitative data easily becomes voluminous. Using N4 and Nivio 1.2 was time-consuming but fostered rigour in the analysis and contributed to making the analysis process traceable and verifiable. During the analysis, N4 and Nvivo 1.2 made it easy to view a great amount of data from new and diverse perspectives.

With the aim of confirming the emerging theoretical constructions, participants from Study I and II were asked to participate in focus group interviews. Most of the Turkish-born, but not the Swedish-born, participants responded negatively to this request saying that health is a private matter only suitable to be discussed with a professional but not with laypersons. Due to the response of the Turkish-born participants, the idea of focus group interviews was dropped and follow-up interviews were used as a form of member-

check with regard to verification and confirmation of theoretical understanding. For Studies I and II this verification and confirmation was made in the follow-up interviews one year after the first interview sessions. An additional member-check was conducted when the results were presented orally and in writing (in the form of the licentiate thesis) to each participant before the start of Studies III and IV. Participants gave positive responses to the content. Participants were subsequently provided with a paper in Swedish (Bäärnhielm, 2001).

Language was a constant issue during the studies, as it was through language that the participants conveyed their experiences, messages and meanings. Angel and Thoits (1987) suggest that individuals inherit structured vocabularies of health and illness from their cultures, which limits the possibilities for the interpretation of physical and psychological states, and structure help-seeking options. There is a link between the availability of appropriate words for emotions and how easy it is to distinguish between experiences (Leff, 1973). Culture and historical influences inevitably affect and change the meaning of words and phrases, and lay and professional meanings may come into apposition (Westermayer and Janca, 1997). Discussing linguistic equivalence across languages, Westermayer and Janca (1997, pp. 297-298), point to the problems with emotional expressions and state, "Symptoms that are subjectively experienced are often not easily translated into numerous languages. These include sadness, anger, anxiety, pain, boredom, weakness and fatigue. Still, it is possible to express subjective experiences across languages, even though phrases of even lengthy explanations may be required."

In the studies with the Swedish-born participants, the meaning of lay language was a constant issue and sometimes had to be discussed during interviews. With the Turkish-born participants linguistic issues were more complicated as they often either used their second language and/or an interpreter. Translation, interpretation and meaning of language became constant issues among the Turkish-born participants. One participant spoke fluent Swedish but wanted a Turkish interpreter so that nothing would be misunderstood. During the interviews, participants sometimes corrected the interpreters and wanted to discuss the correct nuances and meanings of words. Back-translation of some parts of verbatim transcripts was made for quotes, important concepts, words and expressions and just as checks. The quotations used in the papers have been double-checked and the English translations were back-translated. In one interview with a Turkish-born participant (Study II), it was discovered that the participant's emotional

language had not been correctly translated. The mistakes may not have compromised the main communication during interviews but highlight the problem with translation and interpretation of emotions.

#### Study V, validity

Validity of findings from focus group research is related to the quality of data and analysis. The complex character of performing focus group research and of the analysis entails several threats to validity. This was taken into account by making the analysis rigorous, describable and traceable (using Nvivo 1.2). Besides discussing content and inductive coding with Solvig Ekblad, colleagues in a research group, supervised by SE, not involved in this study but with experience of focus group research, read part of the data, discussed procedures of analysis, and were involved in interpreting data and coded parts of the material.

Interactive member-checks were used to maintain the quality of results. Member-checks were made in four steps. First, after each interview session the observer made an interpretative summary of key points of the discussion. Secondly, preliminary results were presented to the unit directors of the participating units (three of the four directors participated in the interviews). Third, results were presented to participants at meetings at the respective unit. Results were confirmed but corrections of nuances, clarifications, new reflections, and more information were added. Fourth, before submission of the first version of the paper each participant in the focus group interviews was given a copy of the manuscript and time to give feedback. At one of the settings, the English manuscript was translated orally into Swedish so that all the participants could understand its content. The results were confirmed by all the participants although one stressed her opinion that it was not the caregivers who should adapt to the patients but the patients who should adapt to Swedish society.

#### Presenting the studies

One part in the process of verifying the validity of results has been the presentation of the studies. This has included discussions of methodology, and presentation and discussion of preliminary and final results. On November 1997 design, methods and the first preliminary results of Studies I and II were presented at the “National network: Migration and Health for applied research”, at Karolinska Institutet. Methods of the studies were presented at the seminar “Somatization and illness meaning, a presentation

of two qualitative studies” at the Stress Research Unit at the Karolinska Institutet and IPM in spring 2000. After the licentiate thesis, results of Studies I and II have been presented at several seminars, course and the “Hälso- och sjukvårdsstämman” April 2001. A summary of results has been presented in a paper in Swedish (Bäärnhielm, 2001). The studies have been commented upon in a discussion about somatization in Sweden (Ekblad, Bäärnhielm, Theorell, 2002).

The results of Studies III and IV were presented, together with preliminary results from Study V, at the annual scientific meeting entitled “Disparities in Mental Health” for the “Society for the Study of Psychiatry and Culture” September 2001 in Santa Fe, New Mexico, USA. The title of the presentation was “In unfamiliar territory: Caregivers’ encounter with somatic communication of mental ill health in a multi-cultural Community”. A workshop about the focus group research method was presented at the Pre-Conference entitled: “Measures and Measurements in Cultural Psychiatry” Albuquerque New Mexico, USA, September 2001. The title of the presentation was “Using Focus Group Research in Cultural: Strengths and Limitations”. Results from Study V and comments on Studies III and IV were presented at the “Congress of the Association of European Psychiatrist” in the symposium “Transcultural Psychiatry”, Stockholm, May 2002. The title of the presentation was “Caregivers’ encounter with somatic communication of mental ill health in a multi-cultural community”.

A presentation of qualitative research and ethics was made at the World Congress of Psychiatry, August 2002 Yokohama, Japan, in the symposium “Introducing qualitative research in cross-cultural mental health research”. The title of the presentation was “Qualitative research, culture and ethics”. A presentation of results of Studies I-V, together with a discussion about implementation of qualitative research, was made at the Fourth International Interdisciplinary Conference Advances in Qualitative Methods, May 2003, Banff, Canada, arranged by the International Institute for Qualitative Methodology. The title of the presentation was “Implementing Qualitative Research Results in Mental Health Care” in the symposium “A symposium on the implementation of qualitative methods in training, clinical work, and as a complement to quantitative methods.”

## RESULTS

*“I feel that I have something like a ball here [points to her neck], that causes harm even in my neck and under the ears.... They call it anxiety. I do not know. I believe that it is. As I do not have any other choice, I have to believe in what they say. Now I have the symptoms and I read about it in brochures and can see that it is symptoms of anxiety. But I did not have the symptoms earlier.”*

Havva (Paper II, p. 445)

This presentation of results will summarise and focus on the major theoretical aspects of the findings of the explorative studies (Papers I – V). For a broader and more contextualised presentation of results, I refer to the papers presenting the respective studies. The papers have been written with the ambition to convey results in a contextualised way.

### **Studies I and II, results**

Studies I and II explore structures of illness meaning. Results are presented in the framework of different agendas for understanding, i.e. the agenda of the clinicians and the agenda of the Swedish-born and Turkish-born participants with the focus on the patients' perspective. Medical records were collected to reflect the formal opinion of the caregiver. In both studies, the caregivers emphasised a psychological agenda of understanding illness. The expression “psychological agenda” refers to both psychological and psychiatric conceptualisations and attributions. In the interviews, the concepts “psychological” and “psychiatric” were used interchangeably but with the common essence of a body/mind split. This is further discussed in Paper III and Paper IV. The information conveyed by the clinicians is described only from the participants' point of view.

In Study I, with the Swedish-born participants, health was expressed through bodily symptoms, a wide range of emotions and by psychiatric and psychological concepts. Attribution patterns were characterised by causal explanations and often several non-competing explanations. Three main healing resources were used; health care, alternative care and self-care. Most participants' illness beliefs and attributions changed, as a result of the contact with health care, from explaining physical symptoms in terms of somatic origin to considering additional emotional and psychological explanations. Psychological conceptualisations came to be regarded as tools for understanding and for

giving access to the use of new healing strategies. The social context was experienced as contributing to an enhanced understanding of illness.

In Study II, the Turkish-born participants communicated health and distress by concrete expressions about the body, emotions, social and life situation. Pain was often lateralised to one side of the body and the heart, a way of expressing distress. Attribution patterns were characterised by verbalising links of coherence between health and aspects of life. Psychiatric attribution of physical symptoms was rarely accepted or valued as a tool for recovery, or as helpful in linking physical symptoms to emotional distress. Three main healing sources were used; medical care in Sweden and in Turkey, and traditional treatment. Relations, to family and the clinician, were regarded as important to recovery.

The encounter with local health care had introduced the participants, of both Study I and II, to new concepts, treatments, new meaning of familiar concepts, psychiatric and psychological attribution of physical symptoms. Notions and beliefs changed in a variety of ways. The Turkish-born participants described a lack of education and difficulties in understanding basic use of medical words. Several expressed difficulties in understanding caregivers and treatments whereas some spoke of positive experiences of learning and re-valuation, and of obtaining new tools for dealing with illness and distress. Although experiencing varying degrees of difficulty, participants actively tried to grasp the meaning of the caregiver. The family played an important role in providing social and emotional support.

In both studies, results highlight a situation in which participants initially gave their illness another meaning than that held by their caregiver. Participants actively tried to grasp the meaning proffered by the caregiver. Different interpretations of illness meaning by patient and caregiver constitute a situation of different realities according to the significance and social reality of the illness. Results of the two studies pointed to a need for enhanced knowledge about how people make sense of: illness, clinical encounters, different perspectives of illness and healing, and the role of the social context with regard to both mental health care delivery and mental health promotion in multicultural settings. For clinical care, results indicated a need to explore the transaction of meaning between caregiver and patient. Results of Studies I and II pointed to the importance of a further exploration of how the participating women had received and incorporated their caregivers' therapeutic intervention of a psychological language of distress and of gaining an insight into caregivers' experiences and in how they imparted their professional agenda of illness meaning.

From the results of the two first Studies (I and II), two more general questions about mental health care for immigrants in Sweden were formulated: How do patients, in an immigration context, with the situation of being uprooted, dislocated and relocated, make sense out of available mental health care? Can one outcome of healing experiences for migrants be a loss of one's own earlier functional ways of understanding, communicating, and dealing with distress whilst at the same time not having access to the ways of the new host society?

### *Historical reflections*

The participants' illness narratives made me curious to consider the data from a history of ideas' perspective. It seemed as if expressions, symbolic meanings, values and treatment traditions had roots that could be traced back to ancient historical and medical traditions. This has not been presented in Papers I and II. Some comments are made in my licentiate thesis (Bäärnhielm, 2000). It was beyond the scope of studies to make an analysis from the perspective of history of ideas. Some fragmentary aspects of influences of Greek and Islamic traditions regarding physiology and medicine among the Turkish-born participants will be discussed together with some comments on historical traditions in Sweden. This is not only to reflect the complexity of constructing illness meaning but also to show that what at first seemed to be incomprehensible, to me as a researcher and outsider, could be given rationality within another framework of ideas.

The Greek physician Galen (130-200 AD) restored and elaborated Hippocratic medicine. Galen's work was spread throughout the Roman and Arabic world and large parts of it was translated into Arabic (Helman, 1998). Greek medicine has had a major impact on Islamic medicine (Good, 1997). Analysing classical Greek and Islamic physiology and medicine, Good refers to classic texts of Galen and Islamic theorists such as Ibn Sina (Avicenna)<sup>21</sup>. Good identifies "warming" as a central metaphor, generative of much of the theorising in Galenic-Islamic traditions. According to Good, a central intellectual problem for Greek and Islamic medical theorists was the transformation of the "natural" into the "vital", raw aliment into vital tissue. "Heating" or "cooking" of food served as a model of transformation in the theory of digestion. When food was eaten it was considered to undergo "heating" or "cooking", first in the

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<sup>21</sup> Avicenna (Ibn Sina 980-1037) a Persian physician and philosopher who wrote an encyclopaedia that was translated to Latin. He was considered a medical authority in Europe. It has been suggested that his ideas are based on the medical theories of Galen and Aristotle (Russel, 1994).

stomach and then in the liver, where it is transformed into the four humours of blood, phlegm, yellow bile, and black bile, and finally into living tissue. Good points to the difficulties of translating the humoral concepts, as this requires considering the historical context. Treatment by cupping like bloodletting, enemas, sweating and other techniques were based on the evacuation of a morbid humour.

The Turkish-born participant Havva (Paper II, p. 443) spoke about her use of cupping. Before Havva consulted primary care, she tried to cure herself using natural water from hot springs in Turkey. When this did not help she tested what she called “an old custom” whereby hot glasses were put on her back in order to draw fluid from the flesh. Illness narratives of the Turkish-born participants often included humoral concepts like hot water, hot springs, taking a hot shower and weather. The participant Tülin suffered from pain lateralised to the right side of the body. During the interviews she was asked about what she thought could help her. Tülin said,

*“I think to myself that I come from a hot country and have not been there for a long time. Maybe going back to that warmth could help my pain. Maybe I can’t tolerate the cold weather in this country. I have noticed that this summer when it was hot here, it helped against my pain. Then I thought that it’s warmer in Turkey and I could have more help ... there are other hot countries too.”*

Tülin referred to humoral factors as having an impact on pain. She formulated a polarity between hot and cold. According to Good (1997), “warm” and “cool”, along with cooking, were part of a central metaphor of mediation and transformation in Galenic-Islamic medical theorising.

For the Turkish-born participants pain, was often lateralised to one side of the body, often the right side. During my clinical work at the clinic in Spånga, I often met this distinct lateralisation of distress among patients, both men and women, of different ethnical background originating from Turkey. The same observation has been made in a previous study of local primary health care, the same area as in these two studies. Turkish migrant women, participating in a rehabilitation programme for young immigrants, reported pain in one half of the body, either the left or the right (Löfvander, 1995). Geoffrey Lloyd (1973) described the great influence of the symbolic polarity of left and right in ancient Greek theories. Right was connected with male and left with female, and the right side was deemed superior to the left. Lloyd regarded the values

attached to the opposites, right and left, to have a great influence in fifth- and fourth-century Greek philosophy. Right was often assumed to be superior to left, the one good, the other evil; or the one connected in some way with masculinity, the other with femininity, or the one thought to be honourable, the other dishonourable.

The ancient tradition of symbolic meaning given to left and right may also be present in the formation of distress symptoms as a part of a symbolic message in the case of the Turkish-born participants. Helman (1996) describes symbolic messages in terms of a “half-body” concept. He refers to an unpublished thesis by Jadhav<sup>22</sup> who found that in parts of north India the left half of a married woman was believed to ‘belong’ to her husband and his kinsfolk. The women could embody marital conflicts by developing pain, paralysis or other symptoms of their bodies.

The Turkish-born participants talked about heart symptoms, tightness in the breast and fear. Mirdal (1986), in his research among Turkish immigrant women in Denmark, described the expression of “tightness” and that this had both somatic and psychic components. The importance of using the heart as an idiom for expressing emotions among the Turkish-speaking Azerbaijani in Iran has been described by Good (1977). Good et al. (1985) found the heart, as popularly conceived, to be both a central physiological organ, a centre of emotions and to be associated with problems of female sexuality and disordered womanhood in Iranian culture. Good et al. (1985) describe “fright” as an aetiological idiom to explain distress or illness in terms of sudden stress or shock.

Paper II describes how participants differed regarding the way in which they used the heart as an expression of distress, from directly presenting heart symptoms to actively describing how they had avoided talking about the heart so as not to be misunderstood by health professionals in Sweden. Conducting the interviews, I used to start up with a broad question asking about the condition of the interviewee’s health. The participant Fatma, in our first interview session, responded:

*“There is no peace and quiet in my body. I feel pain. That is my health. The pain never passes. It makes me very disappointed, feelings of pressure. I feel it during sleep too. It never passes. Every hour is different. Sometimes my blood pressure rises. I tire easily*

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<sup>22</sup> Helman (1998, p. 17) is referring to Jadhav (1986) Explanatory Models, Choice of Healers and Help-seeking Behaviour. Unpublished thesis. Bangalore: National Institute of Mental Health and Neurosciences.

*and the heart gets affected by this tiredness. When I feel it in my heart then I want to lie down. If I do not lie down there is a risk that I may fall down and perhaps faint. I feel like my heart is hanging somewhere and is dangling. I just want to lie, lie down, if I don't. I will fall and faint. It is that serious."*

At the start of the interviews I was not aware of the tradition of using the heart as a way of communicating emotional distress and problems. It took a while until I started to become sensitive to this expression as something more than its most obvious meaning.

Language is one factor in the construction of meaning and there are semantic links between modern psychiatric concepts and Swedish folk healing traditions that might have an historical influence on the internalisation of psychiatric concepts for the Swedish-born participants. The ethnologist Tillhagen (1958) has described that the Swedish concept of "mod-stulen" is to be found in traditional Swedish folk healing. Literally "mood theft", it describes a condition in which the will to live was stolen. The person became taciturn, reserved, brooding and was in a strange frame of mind. They merely faded away if they did not commit suicide. Tillhagen (1958) further reports that there was a special form of the illness designated "sunken" (nersatt – Swedish). These descriptions are both linguistically and conceptually related to modern views and conceptualisations like mood disorder. The word depression is derived from Latin roots meaning press down (Kleinman, 1996).

Examining women and medical care at the turn of the nineteenth century, Johannisson (1998) describes a close interaction between ideas, development of ideas, care and illness expressions. Something of this can be gleaned from Ljungberg's thesis about hysteria from 1957. An appendix to his thesis includes brief case vignettes about patients born between 1860 and 1925. Reading the vignettes gives me an impression of changes not only regarding psychiatric assessment and social conditions, but also regarding illness expressions.

It would be interesting to make a further analysis of data from the studies of this thesis from the perspective of the history of ideas. This might contribute to understanding how the participants made sense of their illness and suffering in interaction with traditions, current experiences, and the social context. Such an analysis might pave the way for a deeper understanding of the process of re-structuring illness meaning.

### **Studies III and IV, results**

Studies III and IV explore restructuring of illness meaning among participants who had encountered caregivers imposing a message of a psychological language for understanding their distress. Study III explores restructuring among the Turkish-born participants. For these participants, restructuring included loss of earlier meanings given to illness, shifts in expressions and healing strategies, and a push towards restructuring illness and suffering into a psychological or psychiatric framework of understanding their distress. In many ways, restructuring had been a disruptive and complicated experience. In their everyday context, participants were engaged in bridging gaps between different perspectives of looking upon their illness. They had poor support from their social context in creating coherence between frames of meaning.

Discussing the results of Study III, I have suggested that when considering the clinical encounter, transaction of meaning and the process of restructuring illness meaning, in the stressful situation of illness, Antonovsky's (1988) Sense of Coherence (SOC) concept may be of relevance. I have further suggested that when participants received a new message of illness understanding this needed to be made comprehensible, manageable, and meaningful in relation to their contextual situation of expressing, experiencing, understanding and giving meaning to distress.

Exploring restructuring of illness meaning among the Swedish-born participants in Study IV, two major trends were identified. First, a trend of accepting a psychological language of understanding distress and secondly, a trend of paying attention to stress and demanding work conditions. The term "burnout" was introduced. Burnout, and related terms, were not imbued with as heavy a meaning as a psychiatric term such as depression. New causal explanations were added to earlier attributions and non-competing explanations were retained. For participants, giving meaning to illness had been a continuous and interactive process in which new meanings had been integrated within a framework of both constancy and change. Restructuring illness meaning had not been uncomplicated. Participants tried to bridge illness perspectives and treatment strategies within their daily life situations of handling distress. The social context had been important for bridging gaps in illness perspectives and in creating coherence between frames of meanings.

When discussing the results of Study IV, I have, as in Study III, suggested that Antonovsky's (1988) Sense of Coherence (SOC) concept may be useful when considering the clinical encounter, transaction of meaning and the process of

restructuring illness meaning. The results of Studies III and IV also shed light on how complicated and interactive making meaning of illness may be for patients in the clinical encounter and that the outcome of the process of restructuring illness meaning probably affects patients' recovery resources.

### **Study V, results**

Study V explores the experiences of caregivers in encountering patients communicating mental ill health via physical symptoms. The study also considers the meaning given to these encounters by the caregivers and their experience of imparting a professional agenda of illness meaning. The presentation of results focuses on the encounter with the multicultural population. Caregivers in all settings, including the primary care setting situated in the Swedish-born middle-class area, found bodily signs and symptoms to be a common way of communicating mental ill health, emotional distress, and social problems. Caregivers encountering a multicultural population (primary care and psychiatry) found that communication was not limited only to these areas. The caregivers considered that that patients' bodily language of expressing distress was used over a broad spectrum.

Caregivers found many barriers for communication with patients from the multicultural suburbs. An important barrier was that of shared language. The caregivers in the multicultural area often experienced that patients gave unfamiliar meanings to symptoms. The caregivers found it difficult to decode patients' bodily language of distress and to know how patients in their turn understood them. Another important obstacle to perceived communication was that of lack of trust. In the multicultural area the caregivers experienced that the patients felt distrust towards society in general and to the health care system in particular. In order to make treatment possible, caregivers in the multicultural suburbs stressed the basic importance of actively constructing a working alliance with each individual patient. In primary care, when professionals in the clinics serving the multicultural suburbs had ruled out somatic origins to symptoms, they often found themselves to be "stuck," finding it difficult to relinquish a bodily frame of communication. These perceived shortcomings concerned treatment of mental ill health in general and were reported also from the primary care setting situated in the Swedish-born middle-class area.

Regarding the caregivers' experience of imparting their professional agenda of illness meaning, it is suggested that the caregivers were in different ways making efforts to

create some form of coherence between their medical model for understanding patients' illness and the meaning given to illness by patients. In bridging gaps of meaning, caregivers lacked support from organizational structures and from shared formulated models for adapting their work to a multicultural population and for treating mental ill health in primary care. It is further suggested that results of the study indicate how caregivers' responses may contribute to patients using a bodily idiom for emotional distress and social problems.

## DISCUSSION

*It is also in the margin of disability that therapeutic change may make a small difference that becomes all the difference in a person's life, a small importance that repairs, rebuilds, reinvigorates, reinvents."*

Kleinman (1995, pp. 3-4)

This discussion of the five studies will start with some comments on their theoretical framework. This will be followed by discussions on methodology, and methodological limits and strengths. The results will then be discussed with some comparative comments on the studies, the sense of coherence concept, and restructuring illness meaning. Finally, the caregivers' situation will be discussed. This section will be followed with concluding remarks about implications for practice and future research.

### **On theoretical framework**

#### *Somatization*

The definition of somatization adopted in this thesis, and the concept of somatization itself, include viewing psychologization, which involves verbalisation and psychological and/ or psychiatric attribution of emotional distress, as a normative style and pathway for communication and medical help seeking. The adopted definition reflects my way of approaching and understanding the concept of somatization at the start of these studies. The definition was chosen as I found it to be a proper way of categorising and understanding a style of clinical communication of emotional distress and of help-seeking among patients.

Conducting the studies has made me rethink the concept of somatization. Now, at the completion of the studies, my way of looking at the concept of somatization, and the adopted definition, has shifted towards that of seeing a need for a broad understanding of patients' communication and the adopted definition as one perspective of interpreting patients' bodily language of distress. Today, I think that the benefit of having used the adopted definition is that it mirrors a historical time and a prominent clinical and contextual way of understanding and handling patients using a bodily language for communicating emotional distress.

Regarding somatic symptoms, Kirmayer and Young (1998) suggest that they are located in multiple systems of meaning that serve diverse psychological and social

functions. They suggest that, depending on the clinician's interpretative stance, somatic symptoms have been conceptualised and handled as: a) an index of disease or disorder; b) a symbolic expression of intrapsychic conflict; c) an indication of specific psychopathology; d) an idiomatic expression of distress; e) a metaphor for experience; f) an act of positioning with a local world; and g) a form of social commentary or protest. Discussing the concept of somatization, Swartz (1998, p. 136) formulates the question "Somatization: patient problem or practitioner construction?" and identifies the clinician's task as, "The challenge is not so much to find out who somatizes and who does not, but to incorporate an understanding of the meanings of somatization in all clinical work" (Swartz, 1998, p. 139).

### *Explanatory models*

The design of the studies was inspired by Kleinman's (1978; 1988) explanatory model (EM) approach. The two first studies (Papers I and II), exploring illness meaning, started with an interest for surveying patient's explanatory models of illness. Early in the studies it became evident that approaching the participants' understanding and perspective of illness had to be done in a broader frame than that of the EM model. It had to be done from their experiences. In listening to participants' illness narratives it became possible to probe for understandings and meanings given to illness. As a result of this, the term "illness meaning" was used instead of referring to patients' EM. In Studies I and II, the aim was formulated as exploring structures of illness meaning. Today I consider that the term illness meaning would have been more appropriate than "structure". This is because illness meaning embraces how people give meaning to illness. In the later studies, III and IV, the term illness meaning is used.

In his later work, Kleinman (1995, p. 8) speaks about his critique of, and ambivalence to, his own Explanatory Model theory and refers to the model being misapplied as an entification of medical meanings as "beliefs", such as things that can be elicited, often outside the vital context of experience. He says that the model was intended to be a device that would benefit meanings, especially the voices of patients and families, and that would create respect for differences. He also regards the EM as a model for clinical self-reflexivity and voices the opinion that ethnography has moved beyond the early formulation of EM. The term illness meaning also comes from Kleinman (1988). Discussing illness meaning he suggests that illness may be given several distinctive senses and that illness experiences and events usually radiate to more than one meaning.

The importance of the meaning given to symptoms is formulated by Kirmayer (1994, p. 183): “The meanings given to symptoms –*any* meaning –serves to turn back the tide of chaos and bafflement that confronts us in affliction. Given specific meaning, illness becomes metaphor - a rhetorical resource to be used to explore and communicate the wider significance of our predicament.”

## **On methodology**

### *Choice of methods*

The data collected in the studies have been analysed with a grounded theory approach except in Study V where data were first indexed according to topic, using a content analysis. The use of other qualitative methods than grounded theory may have led to the identification of other aspects of participants’ meanings and experiences. The cultural sensitivity of grounded theory has been questioned, and grounded theory studies criticised for neglecting descriptions of culture (Morse, 2001). Other qualitative approaches may have captured other parts of participants’ cultural context, sense making of illness, and re-structuring of illness meaning (Papers I-IV) as well as the experiences and meanings of professional caregivers (Papers V). A phenomenological<sup>23</sup> methodology might have described more of the essence of experience and the behaviour. Ethnography<sup>24</sup> could have been an alternative methodology for the exploration of meaning but might not have captured the active and interactive aspects of giving meaning to illness. However, it may have contributed to a better description of the participants’ cultural context.

Analysing the data using a grounded theory approach contributed to maintaining the focus on the active and interactive perspective of participants’ meaning making. This approach also contributed to creating a theoretical understanding. By examining other parts of the interactive process between participants and the caregivers there may have

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<sup>23</sup> Morse and Field (1995) denote the objective of phenomenology as describing the essence of behaviour, based on meditative thought, with the purpose of promoting understanding. The method is considered to be both philosophy and a method originating from philosophy using the work of Husserl, Heidegger, Sartre and Merleau Ponty. The phenomenological tradition seeks to understand the life experiences of the individuals and their interactions within their “life-world”, and the goal is to provide an accurate description of the phenomena being studied.

<sup>24</sup> Morse and Field (1995) denote ethnography as evolved from cultural anthropology and differentiated into several types with the common characteristics of being, holistic, contextual, and reflexive, and with a generalised approach of developing concepts and understanding human behaviour from the insider’s point of view.

been a greater focus on illness experiences or on other aspects of the interaction between participants and caregiver, or on the role of the social context.

### *Limits and strengths*

One of the limitations of this thesis is that it only includes studies using qualitative methodology. On the other hand, the design, with several qualitative studies examining the clinical encounter in a local area, has made it possible to gain an insight into a complex interactive encounter, and to formulate hypotheses grounded in data that include diverse aspects. However, the insight into the clinical interaction is limited and important aspects of the interaction, such as the direct interaction between the participating patients and their caregivers and the response of the social cultural context to participant's illness, are not explored.

Another limitation is that interaction and meaning making are only explored on an individual and group level. For survivors of torture and related abuses, Silove (1999) has suggested a model (revised by Lindencrona, Johansson Blight and Ekblad, 2002) pertaining to threats to physical safety and security. This model has a simple framework in which five fundamental systems are threatened or disrupted; the safety system, the attachment system, the justice system, the existential-meaning system and the identity/role system. Repair of these systems is the focus of multi-modal forms of psychosocial rehabilitation. These systems in turn comprise five different levels of action on which health may be benefited: the individual level, the interpersonal level, the organisational level, the community level and the policy level. Silove's model of identifying several levels and systems involved in interaction may also have relevance for the experiences of illness and encountering health care for people in a immigration situation. It indicates the need for research on different levels. With regard to the present studies, the importance of recognising several levels of interactions has been taken into account by presenting the results together with current research about immigration, mental health, and mental health care in Sweden.

The studies include inherent limitations in becoming acquainted with and interpreting participants' meaning. In Studies I - IV data, collection was influenced by the cultural and social relation between participants and myself as a researcher and women, (being Swedish and having the dual role of a female researcher and physician). Brody (1981) is of the opinion that a researcher, from a dominant society, conducting research with an ethnic minority group, is excluded from full participation in the symbolic experiences of the

participants and the ethnic society and that this impairs the adequate transmission and reception of meaning and its integration with experience.

The cultural construction of the studies (Papers I-IV), with me as a Swedish-born non-Turkish speaking researcher, physician and women, can be assumed to have had various impacts on the results. In the studies with the Swedish-born participants (Papers I and IV), as a researcher, I shared gender, language and ethnicity, but for most of the participants, not socio-economic status. Cultural closeness between the Swedish-born participants and myself was a challenge in the form of a shared context of lay person illness ideas, expressions, meanings and underpinning of statements. This increased the risk of taking things for granted instead of probing and clarifying. In the studies with the Turkish-born participants (Papers II and III), as a researcher, I was excluded from full participation in symbolic experiences and linguistic understanding. On the other hand, for the Turkish-born participants, the distinct transcultural situations facilitated probing and clarification, as nothing could be taken for granted. The design with parallel studies, including data sets from different periods of time, counteracted taking anything for granted, and facilitated making comparisons and probing.

The social construction of the studies (Papers I-IV), with me having the dual affiliation of researcher and psychiatrist, influenced the direction of topics in focus during the interviews. Angel and Thoits (1987) suggest that it is likely that many individuals would hesitate to admit to strangers the use of practices that are generally recognised as unsophisticated. In Studies I-IV my dual professional affiliation influenced the direction of interviews by either opening up or closing certain topics. An important theme during the interviews was the participants' efforts to understand their caregivers, and their interaction in receiving caregivers' psychological language of distress. My impression is that my professional background and close affiliation to the local health care system frequently led to this topic being broached. The participants used the interview situations to talk about their perspective and to ask questions. I got the impression that my affiliation to the local health care system contributed to making participation, involving the sharing of experiences and meanings, understandable and meaningful. It gave participants an opportunity to relate personal experiences, reflections and opinions to caregivers, and this was deemed important.

The gender construction, i.e. only women participated in the studies exploring illness meaning (Papers I and II) and restructuring of illness meaning (Papers III and IV) can be regarded as both a limitation and a strength. On the one hand results are restricted to that

of women's experiences and meanings and on the other this restriction made it possible to become acquainted with female patients' own perspective. My impression is that being a female interviewer made it easier for both the Swedish as the Turkish-born women to share personal experiences and thoughts with me. In the interviews with the Turkish-born participants, both male and female interpreters were used. The participants were given the opportunity to choose interpreter.

Another limitation is that, in the study exploring caregiver's experiences and meanings (Paper V), it is reasonable to suppose that it may be sensitive for professional caregivers to talk about clinical experiences, practices and ideas involving problems and insufficient care. This involves a risk of public scrutiny and criticism. There were initial difficulties in starting up the interviewing with caregivers. After the first interview sessions, participants said that being interviewed had contributed to new perspectives on their work and it became easy to recruit new participants.

One strength with the studies (Papers I-V) is that the research process made it possible to pursue questions raised earlier in the process. Other strengths are the conducting of studies in parallel (Study I parallel with Study II, and Study III with Study IV and V) and that the fact that the individual interviews were conducted over a long period of time (1997-2001) and were followed by a period of writing, comparing and summarising (2002-2003). The parallel study design was time-consuming but contributed to a rich set of data that could be used for continuous questioning and for comparison in the analysis process, as well as in theory construction. The long time span made it possible to establish trust, to have time to analyse data, check up and to notice differences, changes, as well as clarify and validate findings. Another strength is that the same supervisor, Dr Solvig Ekblad, has followed all the research projects and that I, as researcher was not involved in the participants' medical care or treatment. An additional strength is that the methods and preliminary results have been presented in a dialogue with international colleagues.

An additional advantage was that interviewing was carried out in contexts familiar to the participants. The Swedish and Turkish-born patients chose the location for the interviews. The interviews were often conducted in participants homes. This empowered the participant and allowed me to become acquainted with illness experiences and meanings expressed in the participants' daily life-context. The caregivers were interviewed at their workplaces with their daily work situation "outside the door". This was probably both empowering for the interviewees and facilitated obtaining

information rooted in their everyday clinical work. However, the major strength with the studies is that the participants, patients and caregivers, were open and willing to share their experiences, meanings, and thoughts.

## **On results**

### *Comparative comments*

Some comparative comments will be made on the results of Studies I and II and then on III and IV. Even though the studies were conducted in parallel, with the same research question, the intention was to analyse and present the results from each individual study. No attempt was made to match the two groups, and the aim of sampling was to obtain comprehensive and relevant data for each study. There are major social differences between the groups not solely with regard to immigration, ethnicity and cultural affiliation. The Turkish-born group is ethnically mixed as opposed to the Swedish-born group. The Swedish-born participants were older (mean age 47) than their Turkish-born counterparts (mean age 35). The Swedish-born participants had a longer education (mean 8.2 years of school education and with half of the group having a higher education) than those born in Turkey (mean 6.5 years and not one with higher education).

### Studies I and II, comparative comments

The results of the studies indicate similarities and dissimilarities. There were differences in expression of distress between the groups. Pain was often lateralised and the heart used as a way of expressing distress among the Turkish-born. This was not the case among the Swedish-born participants. The Swedish-born participants were familiar with the use of psychiatric and psychological concepts like depression and panic but this was not the case among the Turkish-born participants. The attribution pattern differed between the groups. It was characterised by causal explanations and often several non-competing explanations among the Swedish-born whereas the attribution pattern was characterised by formulating coherence between life events and situations but with little description of verbalising a direct connection of causal attribution among the Turkish-born participants.

In both studies, participants had encountered caregivers conveying a psychological agenda of understanding their illness and initially participants had given their illness another meaning than that held by their caregiver. In both groups, giving meaning to

illness was an interactive process with the clinical encounter having a great impact. An ever present theme in the two groups was participants' efforts to understand their caregivers. The Turkish-born participants described a lack of education and difficulties in understanding basic use of medical words whereas the Swedish-born participants described self-confidence in comprehending and questioning information from health-care services. For most of the Swedish-born participants the clinical encounter had entailed a period of re-evaluation in which, for most participants, attribution changed from explaining physical symptoms in terms of somatic origin, to considering additional emotional and psychological explanations. The re-formulation was regarded as something positive, giving access to a better understanding of illness and new tools for improvement. Several of the Turkish-born participants expressed difficulties in understanding caregivers and treatment although some spoke of positive experiences of learning and re-evaluation, and obtaining new tools for dealing with illness and distress.

In both groups, the medical treatment in the local area was combined with other treatment sources; with medical care in Turkey and traditional treatment among the Turkish-born, and alternative care and self-care and among the Swedes. For participants in both groups the family and the social context played an important role in making meaning of illness and the clinical encounter. For the Turkish-born participants the family had an important role in providing social support. For the Swedish-born participants the social context, not only the family, was regarded as an important resource for enhancing their understanding of illness.

#### Studies III and IV, comparative comments

Restructuring illness meaning had been a complicated experience for participants in both studies and the process included similarities and dissimilarities between the two groups. The introduction of a psychological language of understanding their distress was experienced somewhat differently. For the Swedish-born participants it had been introduced both in and alongside the clinical encounter whereas for those born in Turkey it was introduced solely in the context of their clinical encounter.

The terms psychological and psychiatric were used interchangeably in both groups. Among the Swedish-born participants the terms were partly differentiated, with psychiatric often referring to mental illness. Regarding their use of psychiatric care, the Turkish-born participants had been in contact with the local psychiatric services but had not used any other psychiatric resources in Sweden. This was in contrast to the Swedish-

born participants whom had received psychiatric treatment from local clinics, as well as from other units. In both groups psychiatric treatment was both appreciated and criticised.

All the Turkish-born participants had tried to understand and accept a psychiatric attribution, but the degree of acceptance varied. All the Swedish-born participants had started to pay attention to psychological and psychiatric attributions. Psychiatric concepts like depression, anxiety, and panic had been introduced to both groups. Among many of the Turkish-born participants the term depression had gained an acceptance although it was given various meanings. Among the Swedes, the term depression was accepted for perceived distress and used mainly in communication with caregivers and the close family. The term “burnout” (and related terms) was preferred in communication with a broader social context. The Swedish-born participants used the term burnout widely in contrast to the Turkish-born among whom it had not gained popularity.

The concept of anxiety, and related concepts such as panic and panic anxiety, were used interchangeably in both groups although viewed differently. The Swedish-born participants often appreciated having their distress termed anxiety as this contributed to making their symptoms more comprehensible. Anxiety was not associated with severe psychiatric conditions. For the Turkish-born participants the situation was complex. In Study I the word anxiety was often described as being unfamiliar. In Study III some participants gave anxiety a mainly somatic meaning and accepted others using the concept, whereas others gave anxiety a mainly mental meaning and connected it with stigmatising mental illness. The term panic was used with a degree of familiarity among the Turkish-born participants. It was given a core of somatic meaning but also related to emotional components like fear, breathing difficulties, heart palpitations, tension and strange feelings in the body, and high blood pressure.

Two major trends were identified in the process of restructuring of illness meaning among the Swedish-born participants. First an acceptance of a psychological language of understanding distress and second paying attention to stress and demanding work conditions. For the Turkish-born participants restructuring illness meaning included loss of earlier meanings given to illness, and a push towards restructuring suffering into a psychological or psychiatric framework of understanding distress. Restructuring had in many ways been a disruptive and complicated experience.

In their everyday context both the Swedish and the Turkish-born participants were engaged in bridging gaps between different illness perspectives. The Swedish-born participants described several recourses helpful in understanding and bridging gaps of meaning. The Turkish-born participants, on the other hand, often had to struggle to have their psychiatric contact accepted and understood and received little support from their social context in creating coherence between frames of meanings.

#### *Sense of coherence and restructuring illness meaning*

In the discussion of the results from the studies exploring restructuring illness meaning, III and IV, Antonovsky's (1988, 1993) sense of coherence concept (SOC) is introduced. I have suggested that Antonovsky's concept of sense of coherence (SOC) may have relevance when considering the process of restructuring illness meaning and that constructing coherence between experience, expression, past and new meanings given to illness, may be significant for patients' recovery.

The results of Studies I-IV indicate that the social context has an important role in helping the participants make meaning of their illness. In discussing the results from Study III I have suggested that being in an immigration situation may involve difficulties in keeping up with both the changes in medical values and attitudes in the country of origin and those of the new host society. Restructuring illness meaning with a lack of contextual support for understanding and constructing coherence between frames of meanings makes great demands on the clinical encounter. For patients in an immigration situation, creating coherence between different frames of meanings may be of particular concern. Immigration itself may involve a disruptive life situation affecting such areas as language, social and cultural context, net-work support, contextual responses to illness and coping behaviour, public medical attitudes and discussions, family support, health care delivery and medical practice and so forth. It is thus important that the clinical encounter does not become an additional disruptive experience.

#### *Caregivers' contextual situation*

Results of Study V show that the caregivers in primary care experienced shortcomings in treating mental illness in primary care in Spånga. An international epidemiological WHO study, with 14 participating countries, found 24% of patients contacting general health services to be suffering from well-defined psychological disorders and that 10%

had psychological problems which may not meet the criteria for a formal diagnosis of mental disorder, but diminish quality of life and cause disability (Üstün and Sartorius, 1995). Results from Study V indicate that there might be specific difficulties in detecting, decoding and treating mental illness for primary care services encountering a very multicultural population.

Somatization is suggested to have an interactional mechanism involving both the patient and the response of the clinician (Goldberg and Bridges, 1988). Results from Study V show the interactional dimension of how patients express their distress within clinical encounters. Clinicians failing to decode meaning attached to somatic symptoms and expressions may contribute to interpreting symptoms and expressions in a bodily frame severed from a wider frame of communicating meaning. This may in turn reinforce patients to focus on a bodily communication of emotional distress.

## **CONCLUDING REMARKS**

### **WITH IMPLICATIONS FOR PRACTICE AND FUTURE RESEARCH**

To conclude, the general aim of this thesis has been to explore, understand, and describe how a group of Swedish-born women and a group of Turkish-born women gave meaning to their illness. The participants were in contact with local health care in a multicultural area in Western Stockholm and had been assessed as somatizing by their caregivers. Illness meaning was explored in the first two studies. Results showed initial differences between participants and professional caregivers with regard to illness meaning. To grasp the meaning of the caregiver and to give meaning to illness was an active and interactive process including continuity and change. Results showed the interactive aspects of how participants gave meaning to their illness and the importance of further exploration of participants' restructuring of illness meaning and of caregivers' experiences and perspectives.

Additional aims of the thesis were to explore both the participants' restructuring of illness meaning and the caregivers' experiences of, and meanings given to, encountering patients using a bodily idiom for emotional distress in a multicultural milieu. How the caregivers imparted their professional agenda of illness meaning was also examined. Restructuring was explored in two studies. Results showed that restructuring illness meaning had been a complicated experience. For the Turkish-born participants it had in many ways been a disruptive experience with a push towards restructuring illness into a psychological or psychiatric framework of understanding. For the Swedish-born participants restructuring had been made in two trends, first by accepting a psychological language of understanding distress and then by paying attention to stress and demanding work conditions. The participants were engaged, in their everyday context, in bridging gaps between different perspectives of looking upon their illness. The Swedish-born participants had several recourses whereas their Turkish-born counterparts received poor support from their social context in creating coherence between frames of meanings. From these results I have concluded that Antonovsky's (1988) concept of Sense of Coherence (SOC) may have relevance to the process of restructuring illness meaning and that constructing coherence between experience, expression, past and new meanings given to illness, may be significant for patients' recovery.

Caregivers' experiences and meanings have been explored in one study. Results showed that caregivers found bodily signs to be a common way of expressing emotional

distress. This mode of communication was perceived as an area of conflict with regard to the population in the multicultural part of the community. Caregivers experienced communication problems and difficulties in decoding patients' language of distress. When imparting their professional agenda of illness meaning, caregivers made individual efforts to create coherence between their medical model and patients' understanding of suffering. They reported a lack of support from both organisational structures and clinical models for adapting their work to the multicultural population and for treating mental ill health in primary care.

From the results of these five qualitative explorative studies I wish, from a patient perspective, to formulate the following three hypotheses concerning the clinical encounter of emotional distress and mental illness in multicultural milieus:

- 1) Constructing a sense of coherence between experience, expression, past and new meanings given to illness, may be significant for patients' recovery.
- 2) Regarding the clinical transaction of meanings, for the disruptive experience of illness, restructuring patients' illness meaning needs to be carried out in such a way as to facilitate for the patient to construct a sense of coherence between her/his illness meaning and the caregivers' medical framework.
- 3) The individual illness reality of the patient needs to be given an integral and important role as a collaborative resource alongside the medical framework.

### **Implications for clinical practice**

Concerning the clinical encounter, the results of these studies stress the significance of becoming acquainted with patients' meanings associated with their illness experiences. Further, results indicate that it may be important for patients' restructuring of illness meaning to be made with coherence in relation to the contextual situation of expressing, experiencing, understanding and giving meaning to distress. For clinical care in multicultural milieus the results point to the importance of acceptance of working with diversity and pluralism of illness meanings and illness realities in the encounters. Concerning the stance of the clinician in working with diversity and the unfamiliar I would like to refer to the introductory quotation of Kierkegaard.

For caregivers working in multicultural milieus the results of these studies show the importance of support from organizational structures and shared formulated models for adapting their work to a multicultural population and for treating mental ill health in

primary care. This in turn highlights the importance of training in working with cultural diversity for both clinicians and students.

### **Implications for future research**

With regard to research the results of these Studies point to the need for further research exploring interaction between health care and individuals and social and cultural groups in order to obtain insights in how people make sense of, use, and cope with their clinical encounter for recovery. The acquisition of this type of knowledge is of particular importance for patients in an immigration situation, as immigration involves the potentially stressful situation of being uprooted, dislocated and relocated.

## ACKNOWLEDGEMENTS

I wish to extend my warmest thanks to all those who have contributed to make this work possible. In particular I would like to express my sincere gratitude to:

*The participating women and caregivers* who generously gave their time and shared their experiences and thoughts.

*Solvig Ekblad*, scientific supervisor, for your long sincere support of this research, your sound advice and generous gifts of time and knowledge.

*Steve Wicks*, for all your tactful help with the delicate task of transforming my Swedish-English mixture to readable English.

*Karin Gadd*, retired chief consultant of the former Spånga-Kista psykiatriska sektor (Spånga Kista psychiatric sector), for your support in embarking upon the studies.

*Rolf Stackenland*, chief consultant of the former Västra Stockholms psykiatriska sektor, (Psychiatric Sector of Western Stockholm) for your support in the realisation of the studies.

*Anna Åberg-Wistedt*, chief consultant, Norra Stockholms psykiatri (Psychiatric Sector of Northern Stockholm), for your support in completing the studies.

*Siw Lundin, Lotta Hartler, Sara Isabella Ekblad, and Lilian Pettersson* for your careful transcriptions of the interviews.

The *interpreters* for your meticulous translation work and to *Serdar Öztenar* for also helping with the Turkish.

*Gunilla Andersson*, co-ordinator at IMP and Karolinska Institutet, for creating the front-page and support with layout of the texts.

*My colleagues at Spånga psychiatric clinic and the primary care settings in Spånga* for your collaboration and for your clinical work, which contributed to making these studies possible.

The *research group in transcultural psychology* at the Neurotec-Department at Karolinska Institutet, under the leadership of Solvig Ekblad, for helpful methodological discussions during the years of my studies.

*My colleagues at the Transcultural Centre, Stockholm County Council* for our discussions about culture, immigration and health.

*Björn*, my husband, for all the support you have given, and our children *Nanna, Erik* and *Olof*, who through all our funny and noisy discussions, and stories, about multicultural milieus and integration, have contributed to the joy, motivation and energy needed to complete this research.

*Mauritz*, my father, for once engaging my curiosity in entering unknown worlds and in the importance of human rights' issues, and my mother *Ingbritt* for encouragement.

Funding from Public Health and Medical Services Committee (HSN) Dnr 1997-7236, and 2001-7451 Research and Development (FoU) and from the Health Care Area of Western Stockholm (VSSO).

## **EPILOGUE**

These studies started with my wish to explore patients' meaning beyond the confines of everyday clinical work. The research process continued with exploring changes in patients' meaning making and my colleagues' perspective. Now, at the end of this journey and in summarising, I can see that my interest in exploring the meaning of the other is related to my need to be able to make sense of clinical experiences as well as data collected within a research frame. This is rooted in my need to make the world comprehensible, manageable, and meaningful.

For the development of clinical care in multicultural milieus, the research process leaves me with the conviction of the significance of connecting clinical care with a broad research frame. The clinical questions and problems from multicultural milieus should not remain in the margin. These issues need to be seriously investigated so that development is not left at the mercy of social and political trends with the pressure of rapidly making sense of a complex and changing reality.

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## APPENDIX

The interview guides for Studies I-V are presented below. These were used as guidelines to ensure that the interviews cover the same areas with all participants. The guides indicate areas for probing and not for direct questioning.

### **Appendix 1 - Interview Guide for Studies I and II**

#### *1. Health situation*

Tell me about the condition of your health.

How has your health been earlier?

What sort of problem did you have then?

When do you feel well?

#### *2. Understanding and help seeking*

Do you confer with your family about your problems?

What does the family say?

What do you think about that?

Do you confer with friends or acquaintances about your problems?

What do they say?

What do you think about that?

Do you usually confer with others about your problems?

What do they say?

What do you think about that?

Have you been to the doctor about these problems?

What does the doctor say?

What do you think about what the doctor said?

What do you think about everything you hear, how do you think that things are connected with each other?

#### *3. Health and medical care experiences.*

Can you tell me about your contact with the health and medical care services?

What have your expectations been?

What help have you received?

What treatment have you received?

What has been good?

What has not been good?

Do you think that you have been able to say what you have wanted?

Have your views been listened to?

*4. Foreign/Turkish/ health and medical care experiences.*

What contact have you had with health and medical care services in Turkey/abroad?

What have been your expectations?

What help have you received?

What treatment have you received?

What has been good?

What has not been good?

Do you think that you have been able to say what you have wanted to?

Have your views been listened to?

*5. Help contacts outside health and medical care*

Have you sought any other help than health and medical care for your problems?

- help from the family or others in your surroundings?

- help from religion?

- other forms of help?

What help did you seek?

What were your expectations?

What help have you received?

What treatment have you received?

What has been good?

What has not been good?

Do you think that you have been able to say what you have wanted to?

Have your views been listened to?

*6. Own explanation model*

What do you think has caused your problems?

Can you in any way have contributed to the fact that you have problems?

Do you think that factors such as the weather and temperature may have had an effect?

Can there be other reasons for the problems?

*7. Turkish folk remedies*

Can some evil force such as an evil eye have caused your problems?

Have you ever sought the help of a Hodja?

What were your expectations?

What help did you receive?

What treatment did you receive?

What was good?

What was not good?

### *8. Current circumstances*

How have your problems affected your current circumstances?

What has changed?

How were things prior to your problems?

How do you think it would be for you if you did not have the problems you have now?

What have the problems you have meant for your family and relatives?

Have you received any help from the family, relatives, neighbours, or friends?

How does it feel for you that things have turned out like this?

### *9. Illness knowledge*

When you were a child and were growing up what did you learn about illnesses?

From whom did you learn something?

Have you learned anything new as an adult?

What have you learned?

How have you learned this?

### *10. Illness role*

Do you think that it is possible to describe in words how you feel and experience your problems?

Is there any better way?

What does your family say about your problems?

What do your relatives say?

What do you say to your children?

Is there any one in the family who has problems similar to yours?

Do any of those around you have similar problems to yours?

When you notice that you have symptoms can you describe how you react?

How do those around you, your family or others react in such situations?

### *11. Onset of problems*

Do you remember when your problems began?

Do you remember how your life was then?

Can you tell me?

Do you think that there is some connection between how life was then, what happened and the problems that began?

Is there any connection between your life now and your symptoms?

Are there any events or relationships in your life that you believe have had significance for your health?

Can you tell me?

### *12. How to become healthy*

What do you think would be the best help for you?

Are you able to influence your situation so that you get better?

What advice have you been given?

Can this advice be of help to you?

From whom have you received the advice?

What is needed so that you do not become worse?

Are you able to influence the situation so that you do not become worse?

What advice have you received?

Can this advice be of help to you?

From whom have you received the advice?

### *13. The future*

What are your thoughts about the future?

What do you expect?

Do you think that your health can be better?

Do you believe that it will be better?

What do you think that the health and medical services can do for you?

Is there anything else/anyone else that could help you?

What does it mean to you if you get better?

What does it mean to you if you do not get better?

Do you make plans for the future?

### *14. Mental health*

What does mental health mean to you?

How do you regard your mental health?

### *15. Miscellaneous*

We have talked about health, problems and illness. Is there something we have forgotten, which you would like to talk more about?

Is there anything that you would like to tell me that we have not talked about?

## **Appendix 2 - Interview Guide for Studies III and IV**

### *1. Health status*

How is your health at the moment?

How has your health been since we last met?

What treatment have you received?

### *2. Meaning and integration of caregiver's agenda (and social context)*

Can you tell me of some occasion when your caregiver informed you that your problems had a psychological/psychiatric explanation?

What do you think about this?

What do you think about that the fact that the caregiver used psychiatric words like anxiety, depression or others?

How has your caregiver's explanation come to affect your ideas?

Have you come to change your ideas?

Who have you talked with about this?

What have those in your immediate surroundings thought about your caregiver's explanation?

How do you feel that you can manage your problems when they come?

What do you think about the treatment you have received?

Have you felt trust in your caregiver?

What sort of treatment would you like?

### *3. Miscellaneous*

Summary of the interview session

(treatment intervention, treatment relation)

(feeling of coherence, manageability, meaning – in relation to treatment)

Is there anything else you would like to tell me?