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Caring for foreign-born persons with psychosis and their families

Perceptions of psychosis care

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To those involved in psychosis care

Maybe the past is like an anchor holding us back.
Maybe you have to let go of who you were,
to become who you will be.
"satc"

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ABSTRACT

The aim of this thesis was to describe and analyse perceptions of psychosis care among those involved in care, foreign-born persons with psychoses, their families and health care staff, and further to reach agreement about core components in psychosis care. This was in order to find out whether current psychosis care in Sweden is suitable for foreign-born persons and their families.

The study design was explorative and descriptive. Health care staff (n=35), persons with psychosis (n=22) and families (n=26) of persons with psychosis were chosen from different regions in Southern Sweden. To capture health care staff's experiences and to explore whether specific needs occurred within psychiatric care, nine focus group interviews were held. The perspectives of psychosis care among persons with psychoses and their families were captured through individual interviews. Finally, a study was accomplished all over Sweden in which staff, foreign-born persons with psychosis and foreign-born families of persons with psychoses answered a questionnaire to identify core components in psychosis care of foreign-born persons and their families.

There was agreement that the core components in psychosis care concern general psychiatric caring, even though varying perceptions were identified. Asking about foreign-born persons' religious and ethnic background or having the possibility to decide whether care should be provided by male or female staff were agreed to be less important.

No agreement could be reached concerning the importance of considering different perceptions of psychosis care, treatments and different ways of managing the psychosis. Nor could agreement be reached as to whether staff should have specific cultural knowledge and whether interpreters should be unknown to the family but speak the right dialect.

Perceptions among staff in somatic and psychiatric care as well as perceptions among foreign- and Swedish-born persons with psychosis and their families were more similar than different. General psychiatric care is important for Swedish-born as well as foreign-born persons with psychosis and their families, indicating the importance of not letting culturally determined perceptions dictate the care and take away energy from health care staff and make them lose their focus on the basic elements in general psychiatric care. However, within the general care there were individual perceptions on whose importance those involved in care did not agree.
Further development suggested is to illuminate the importance of identifying individual perceptions which may differ between different persons and could be related to cultural background. Staff need to acquire strategies so they can easily manage to encounter and offer general care to foreign-born persons. Development must be achieved on both an organizational level and an individual level.

Keywords: Qualitative methods, migrants, psychosis care, delphi technique.

LIST OF PAPERS

I Hultsjö, S., Hjelm, K. (2005) Immigrants in emergency care: Swedish health care staff's experiences. *International Nursing Review 52, 276–285.*

II Hultsjö, S., Berterö, C., Hjelm, K. (2007) Perceptions of psychiatric care among foreign- and Swedish-born people with psychotic disorders. *Journal of Advanced Nursing 60 (3) 279–288.*

III Hultsjö, S., Berterö, C., Hjelm, K. (2009) Foreign- and Swedish-born families' perceptions of psychosis care. *International Journal of Mental Health Nursing 18*, 62–71.

IV Hultsjö, S., Berterö, C., Arvidsson, H., Hjelm, K. (submitted) Identifying the core components in the care of foreign-born persons with psychosis and their families – Using the Delphi technique.

DEFINITIONS

In this dissertation the term "foreign-born" refer to persons born in countries other than Sweden.

The terms psychosis and psychotic disorder are defined according to ICD 10, code numbers F20–F29 including schizophrenia, schizotypal disorders, delusional disorders, schizoaffective disorders, other non-organic psychoses and unspecified psychoses (World Health Organization 2005).

Exactly who is a family member is defined by the person with psychosis and may include parents, children, siblings, cohabitants and sisters-in-law.

INTRODUCTION

This thesis has its roots in the question: Is current psychosis care suitable for foreign-born persons? To answer this question the triad of persons involved in psychosis care – the person with psychosis, the family and the health care staff – were asked about their perceptions of care, and further to agree about which of those are core components of psychosis care. Why is it important to study this?

Firstly, psychosis is a common mental illness, with a prevalence of about 1% of the population in the world (Jablensky 2000), and with higher risk among first- and second-generation migrants (Cantor-Graae et al 2005b, Smith et al 2006, Veling et al 2006). Secondly, nearly 14% of the Swedish population (9.2 million in total) are foreign-born persons (SCB 2008), so there is a large chance of encountering foreign-born persons in the health care sector and thus in care of persons with psychotic disorders. Thirdly, according to the Swedish Health and Medical Services Act (SFS 1982:763) care is to be given on equal terms to all persons and their families and with respect for the patient's right of self-determination and integrity. Fourthly, it is known that foreign-born persons can carry different perceptions of mental illness and its treatment and care (Helman 2007). Individual perceptions about health, illness and care are culturally determined, based on knowledge held by the individual, revised by experiences, and they form attitudes that guide health-related behaviour and health care seeking (Hjelm et al 2003; Hjelm 2007). Caring for persons with different perceptions of treatment than our own, can cause difficulties in

acquiring knowledge, committing to and engaging with persons from different cultures (Cioffi 2005). Foreign-born persons are very heterogeneous and may have different cultural, ethnic and religious background, and each individual is unique and affected by personal and social factors (Leininger 2006) and can show different degrees of integration and assimilation in the new society (Berry 2005). This affects how the person interacts with the psychiatric health care sector, and therefore it is of primary importance to prepare nurses to provide care to persons with psychoses and their families irrespective of their origin (Leininger 2006; Giger & Davidhizar 2004).

Previous studies have mainly investigated the increased prevalence of psychosis among foreign-born persons (Selten et al 2007), particularly African-Caribbean and Black African groups in the UK (Cantor-Graae 2007; Fearon et al 2006), among first- and second-generation immigrants in Sweden (Cantor-Graae et al 2005; Zolkowska 2001), European immigrants in Canada (Smith et al 2006) and non-Western immigrants in the Netherlands (Veling et al 2006). At the time of this thesis no studies had been found investigating foreign-born persons, families' and staff's perceptions of existing psychosis care, with the exception of studies focusing on culturally adapted models. Those studies found positive outcomes of culturally adapted models of family interventions aimed to reduce stress in families of African and Mexican migrants in the USA (Weisman et al 2003; Snyder et al 2004; Weisman et al 1993; Rosenfarb et al 2004; Morrison et al 1999) and non-European migrant families in Canada (Rousseau et al 2005). They do not represent European migrants, who account for the major part of the Swedish migrant population (SCB 2008). Those studies also illustrate that culturally adapted programmes are best suitable for

the cultures they have been tested for. Therefore in this thesis it is questioned whether culturally adapted programmes are the best solution in a society with a heterogeneous migrant population as in Sweden, where groups of foreign-born persons from the same culture are small. The summarized picture indicates a need of knowledge in the area and the importance to identify whether current psychosis care in Sweden is suitable for foreign-born persons and their families.

Migration and acculturation effects on mental health

Today nearly 14% of the Swedish population (9.2 million) are foreign-born, nearly every fifth inhabitant if the second generation (one parent born abroad) is included. During the year 2008 the largest groups arriving in Sweden were people from Iraq (n=13,083), Poland (n=7091) and Somalia (n=4218), and in total over 220 nationalities are represented in Swedish society. The migrant population in Sweden is dominated by European labour migrants who arrived after the Second World War in 1945, and the largest group of migrants in Sweden are Finns (175,113 individuals) and former Yugoslavians (150,061 individuals) (SCB 2008). The role of migration has changed over the years, and from the 1950s to the 1980s attractive circumstances on the Swedish labour market influenced the pattern of migration and migrants were welcomed. Migration after the 1980s has been dominated by refugees forced to leave their countries due to war and persecution, such as those from Iraq, Somalia and Yugoslavia, who have not been very welcome on the labour market in Sweden (Svanberg & Tydén 2005). The emphasis here is on why the migrants left their homes and whether their migration was voluntary or involuntary. The two pathways to migration often overlap, as one may be "pushed" to migrate to an

impoverished country while "pulled" towards new economic opportunities elsewhere. It is likely that individuals who migrate voluntarily with a motivation to work obtain larger benefits from migration than do those who do not have either of these qualities (Helman 2007). Voluntariness in the reasons for migration facilitates the acculturation process of individuals (Berry 2005).

Acculturation is a process in which an individual with a primary upbringing in one culture adapts new characteristic ways of living from another country. It is multi-dimensional, and the changes to which the individual is exposed when developing a new culture are physiological, biological, political, economic, cultural and social (Berry 1990). Assimilation is when one abandons the old culture to participate in the new one, and separation/segregation when one loses cultural and psychological contact with one's own traditional culture and the rest of society. Sometimes these mutual adaptations take place rather easily but they can also develop into culture conflict and acculturative stress. The acculturation stress is related to the reasons for migration, knowledge about the new society and the spoken language, social support, cultural distance (including dissimilarities in culture, religion, language, standard of living, skin colour, attitudes), individual coping strategies and resources, and the present state of circumstances in the society of arrival (Hull 1979). Acculturational stress may lead to decreased mental health (Berry 2005).

The process of migration is not simple or straightforward. (Hull 1979; Bhugra 2004), and the migrant population may have a history of forced migration and traumatic experiences such as war, torture, rape and persecution (Ottosson 2000; Södergard & Ekblad 1998). Post-traumatic stress syndrome (PTSD), is

common among foreign-born persons, mainly because of traumatic life experiences in their host country (Ottosson 2000). When exposed to changes in a new environment, a person may develop symptoms such as anxiety and depression (Lindert et al 2008; Tselmin et al 2007; Witting et al 2008). If untreated for a long time, symptoms can change for the worse into serious and lifelong diseases and affect quality of life in a negative manner for the individual (Ekblad et al 2000).

It has been discussed whether individuals vulnerable to mental health problems migrate to a larger extent, trying to escape restlessness or stigmatization experienced in their home country (Bhugra 2004). Cruickshank and Beevers (1994) describe how people with diseases sometimes migrate in order to receive treatment in the new country, and some researchers assume that lower socio-economic status, unemployment and loss of social networks in the new country are risk factors for mental illness (Morgan et al 2008; Angel & Hjern 2004; Fossion et al 2004). Findings from other studies illustrate that, among adolescents in the United Kingdom, fewer mental health problems were found in those who were able to integrate and make friends with natives (Bhui et al 2005). Other risk factors for developing mental ill-health among foreign-born persons include abuse of psychoactive substances in some migrant groups (Veen et al 2002). It has been found that foreign-born persons in psychiatric care have more unmet needs than natives (Arvidsson & Hultsjö in press), are less satisfied with their treatment and are treated with higher doses of medication and less likely to receive psychological therapies (Bhugra et al 2004; Bhugra *et al* 2000). A connection has been found between having an immigrant background, committing suicide and less access to psychiatric care

(Ferrada-Noli et al 1996; Saraiva-Leão et al 2005). There is an excess in rates of psychiatric detention of male foreign-born persons compared with natives (Swaran 2008), and it has been found that the incidence of mental disorders is higher among foreign-born women (Bhugra 1997; Ödegaard 1932).

Psychoses among foreign-born persons

It has been shown in studies from several countries that the incidence of psychosis is higher among foreign-born persons than native-born (Cantor-Graae & Selten 2005a; Fearon et al 2007; Veling et al 2006). The increased rate of schizophrenia occurred early in the twentieth century among white migrants from Britain or Continental Europe to Canada (Smith et al 2006). Since the 19th century researchers from all over the world have tried to identify the cause of schizophrenia but still no definite explanation has been found, and it may be debated whether we are really much closer to a significant understanding of the disorder today than in 1886 (Malmgren 2005). Today the main explanation is that the person have an unbalance in neurotransmitters in the brain caused by a combination of genetic inclination and stress (Ottosson 2000). This can only partly explain the increased risk of psychosis among migrants, and other explanations that are discussed are the processes in the early neurological development and increased exposure to other infectious agents in their home countries (Eagles 1991). Further discrimination perceived by ethnic minority groups as in Western Europe may contribute to their increased risk of schizophrenia (Veling et al 2007).

Psychotic disorders are classified through individual behaviour and thoughts (Socialstyrelsen 2005), which can cause difficulties. The classifications about

how to behave proceed from the individual and the society and are influenced by existing attitudes and values in the society (Bhugra 2004; Svensson 1990) and demographic, clinical and familial factors may plausibly influence the manifestation of hallucinations (Knight et al 2008; Thomas et al 2007). When people migrate, problems may arise if they carry attitudes and behaviours differing from those of people in the new country (Helman 2007). Misunderstanding due to different cultural behaviour or barriers to communication have been shown to increase the risk of misdiagnosis (Stolk et al 1998) which can lead to inappropriate treatment (Hjelm et al 2007; Robinson & Gilmartin 2002). We may never be able to fully understand the relationship between the context/environment, the genetic risks and the development of psychotic disorders. This poses a great challenge for health care staff to develop care in order to meet the needs of foreign-born persons.

Psychosis care in Sweden

In recent years, mental health policy documents, programmes and mental health care reforms have been implemented all over the world with the aim of improving the conditions of persons with psychiatric diagnoses. In Sweden a mental health care reform was implemented in 1995 (Stefansson & Hansson 2001). The reform seeks to define the division of responsibilities between social services and psychiatric hospital care, at the same time as both parties must support one another in their respective tasks (Arvidsson 2004). The social services are supposed to make life outside institutions possible for people with certain functional disorders (SFS 1993) and support all those who live in the municipality (SFS 2001), providing them with home care and assistance, close co-operation between the social services and psychiatric health care, the

development of more group homes, the development of day centres and other facilities for daytime activities. The psychiatric health organizations are supposed to put their efforts into adequate treatment methods which are administered adhering to the Health and Medical Services Act (SFS 1982) and the Compulsory Institutional Care Act (SFS 1991).

Even though the structure of care differ within and between countries, the core components in psychosis care today involve pharmacological treatment with antipsychotic drugs to decrease symptoms, empathetic encounters, psychological treatment, training of cognitive strategies, and support to the social network (Socialstyrelsen 2003). Persons with psychosis may need periodic hospital admission, but otherwise care in Sweden is provided on an outpatient basis, at the psychiatric clinics by a team of healthcare professionals including assistant nurses, occupational therapists, physicians, psychiatric nurses, psychologists and social workers. Thus, care of persons with psychoses takes place in three-part co-operation between the person with psychoses, his/her family and health care staff (Leininger 2006). In this thesis the focus is on perceptions of psychiatric outpatient care.

The triad of persons involved in psychosis care

The care perspective in psychosis care is on the person with psychoses. A psychosis is a disability which often leads to the persons being in need of lifelong support from the health care sector (Levander et al 2008). Research illustrates that families take great responsibility for the psychotic person (Foldemo 2004). When families commit to and show a supportive attitude towards the sick person the risk of relapse is reduced (Orhagen & d´Elia 1991;

Pharoah et al 2006). It has also been shown that families express more needs than persons with psychosis (Foldemo et al 2004). This has been documented in forty countries around the world, with the same results between and among different cultures (Weisman 2006). Therefore it is important that persons with psychoses and the family should be treated as a unit and receive health care addressing all members' needs and not only the needs of the patient (Leininger 1995). Thus support from the mental health care sector should be accessible for the family as well as the person with psychosis.

Difficulties may arise when health care staff encounter persons and families with different explanations for illness and different behaviours from theirs (Giger & Davidhizar 2004). As society is becoming increasingly multicultural, cultural issues are also becoming important in the mental health care sector, as all persons have the right to have their background understood. According to the Health and Medical Services Act (SFS 1982:763) care is to be given on the same terms to all persons, with respect for the right of self-determination and integrity. Nevertheless, some research suggests that foreign-born persons are at a disadvantage in psychiatric care (Lay et al 2005; Lindert at al 2008; Saraiva Leão et al 2005; Arvidsson & Hultsjö In press). In order to find out whether current psychosis care is suitable for foreign-born persons and their families, the perceptions of psychosis care from the triad of people involved in psychosis care must be explored.

In the following the triad of person involved in psychosis care involves persons with psychosis, families of persons with psychosis and staff working in psychosis care.

Theoretical framework

A treatment strategy that is consistent with the patients' needs and demands may have a better chance of being successful (Giger & Davidhizar 2004). Therefore it is important to take into consideration the individual perceptions of psychosis care. Perceptions are based on experiences in reality, as humans are aware of and dependent on different cultural and social contexts. The only world a person can express him/herself about is the one experienced. The qualitatively different ways of understanding and experiencing a phenomenon can be described as aspects of a phenomenon that are discerned and simultaneously appear in persons' awareness (Marton & Booth 1997). Depending on the individual perceptions of illness, a person will interact differently in encounters with staff in the mental health care sector. To advocate care that is permeated with respect for other persons' perceptions, it is important that health care staff learn to identify and analyse perceptions of care. Transcultural nursing is about being able to care for persons no matter who they are, what background they have and where they are (Leininger 2006; Giger & Davidhizar 2004).

In this thesis work by Leininger (2006) and Giger & Davidhizar (2004) has been used as the theoretical framework. Giger & Davidhizar (2004) have an individual perspective that focuses on the six cultural phenomena believed to shape care – communication, space, social organization, time, environmental control, and biological variations – which are systematically explored and the variations that follow in caregivers' responses and recipients' perspectives, given the cultural diversity. Leininger (2006) has developed a nursing theory entitled "culture care diversity and universality". The first terms in the title,

"culture care diversity", refer to the variabilities and/or differences in meanings, patterns, values, life-ways or symbols of care within or between collectivities. The second term in the title, "universality", refers to the common, similar or dominant uniform care meanings, patterns, values, life-ways or symbols that are manifest among many cultures and reflect another individual or group derived from a specific culture (Leininger 1995). It was chosen to study similarities and differences among foreign-born persons living in Sweden. As already mentioned, the migrant population is heterogeneous and thus foreign-born persons from different countries are involved. Further, both Leininger (2006) and Giger and Davidhizar (2004) also assume that as a researcher or nurse it is important to take into consideration both the "emic insider knowledge" (the patient's own perceptions) and the "etic outsider knowledge" (what the nurse or other care givers, such as the family, see) in order to give appropriate treatment. Therefore a sample involving health care staff (studies I, IV), patients (studies II, IV) and families (studies III, IV) was studied.

AIMS

General aim

The overall aim of this thesis was to describe and analyse perceptions of psychosis care among those involved in care: foreign-born persons with psychoses, their families and health care staff. This was in order to find out whether psychosis care in Sweden is suitable for foreign-born persons and their families.

Specific aims

- To identify whether health care staff in somatic and psychiatric emergency care experienced any problems in the care of migrants, and if so, to compare their experiences in order to identify whether specific needs occur within psychiatric care.
- To explore different perceptions of psychiatric care among foreign- and Swedish-born persons with psychotic disorders.
- To describe how foreign-born and Swedish born families living in Sweden perceive psychosis care.
- On the basis of previous results, to identify the core components in the care of foreign-born persons with psychosis and their families in order to find out whether psychosis care in Sweden is suitable for foreign-born persons and their families.

METHODS

Method description

In the following the studies will be designated as (I–IV).

Three interview studies and a questionnaire study with the Delphi technique were used to achieve the specific aims (Figure 1). Focus group interviews were held to capture health care staff's experiences of caring for foreign-born persons (I). Individual interviews to capture perceptions of psychosis care among persons with psychosis and their families were conducted (II–III). Finally, an expert group of those involved in psychosis care all over Sweden answered two questionnaires to reach agreement about the core components in the care of foreign-born persons with psychosis and their families.
An overview of the four investigations are found in table 1.

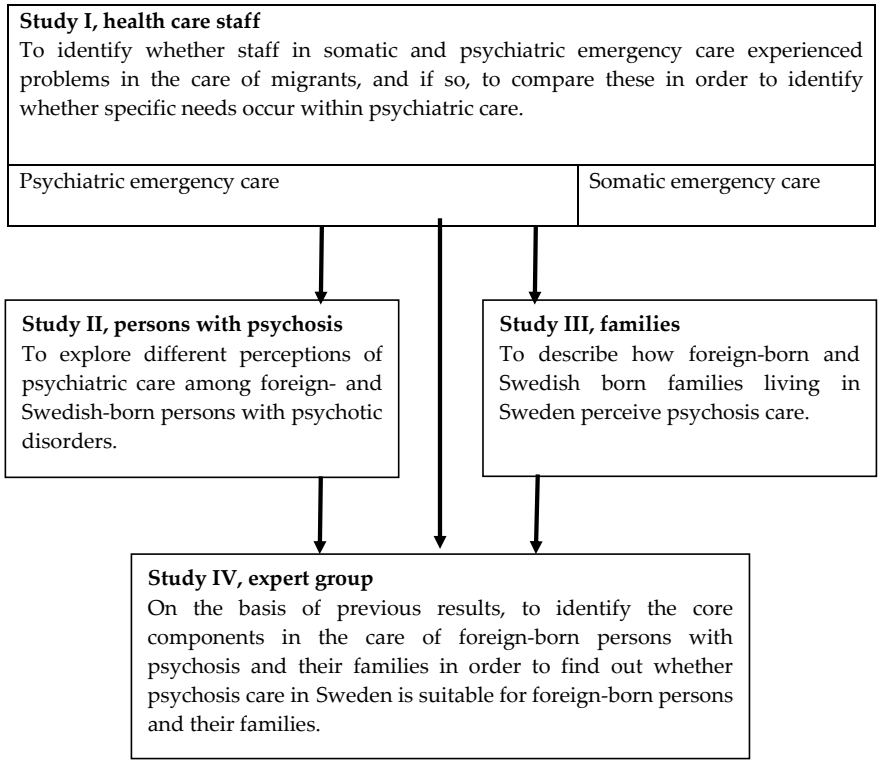


Figure 1. The procedure of the four studies included in the thesis.

Focus groups

As the field has not previously been explored and the study sought to understand the reality, an qualitative method using semi-structured focus group interviews was chosen (Krueger & Casey 2009). A focus group interview is an interview with a small group of persons, usually 6–10 persons of similar background being interviewed about a specific topic (Patton 2002). In comparison to individual interviews, the group situation makes people feel

more secure and they often get "carried away" by the discussions and reveal even unconscious thoughts (Krueger & Casey 2009).

Phenomenography

A phenomenographic approach was chosen. The outcome in phenomenography is the generation of different content-related categories of what is experienced by the participants themselves (1st order perspective). The categories can be seen as a structural framework within which various qualitatively different ways in how people experience the phenomena are described (2nd order perspective) (Marton & Booth 2000). The perceptions are based on experiences in reality, as humans are aware of and dependent on different cultural and social contexts (Marton & Booth 1997).

Delphi technique

In order to identify the core components in the care of foreign-born persons with psychosis and their families on a national basis, the Delphi technique was used. The Delphi technique is a commonly used method for getting a group of persons (experts) to reach agreement (Murphy et al 1998). The aim of the first round is to identify statements (Bond & Bond 1982). The second round is more specific than the first round, as the statements are structured and organized into a questionnaire and informants are asked to rank the importance of statements (Murphy et al 1998). From the second round the informants get feedback about the group's rating. By giving feedback, the informants can see their own rating related to the group's rating (McKenna 1994). The third round

involves feedback on the informants' own and the group's rating from the previous round and ranking of the remaining statements (Murphy et al 1998).

Table 1. Overview of the investigations in the present thesis.

Study	**Study Design**	**Study population**	**Methods for data collection**	**Methods of analysis**
I	Explorative and descriptive	35 health care staff	Focus group interviews	Focus group analysis
II	Explorative, and descriptive	12 foreign- and 10 Swedish-born persons with psychosis	Individual semi-structured interviews	Phenomenographic analysis
III	Explorative, and descriptive	11 foreign- and 15 Swedish-born family members of persons with psychosis	Individual semi-structured interviews	Phenomenographic analysis
IV	Descriptive	43 experts in psychosis care	Questionnaire	Descriptive statistics

Contrasting was used (I–III) as it is a way to draw closer to the meaning of what is studied (Patton 2002). It can be difficult to explain which perceptions occur among a group of persons or within an organization if they are not related and contrasted to something. This makes it clearer which experiences are specific for psychiatric care (I) if they are contrasted with experiences in

somatic care, and it is clearer which perceptions occur among foreign-born persons (II, III) if the perceptions are contrasted with perceptions among Swedish-born persons.

Informants

To capture the qualitatively different perceptions of a phenomenon, a heterogeneous sample of informants is needed (Marton & Booth 2000). Thus to illuminate perceptions of psychosis care from different perspectives, the informants in studies I–IV originated from different countries in different parts of the world (Table 2) and had varying reasons for migration (war, political reasons, persecution, family reasons) and different length of time in Sweden (Md 22 years, range 10–49). Both sexes were represented (77 female and 49 male) and their age varied (Md 46 years, range 22–69). The informants also had varying education and experiences of psychiatric care in Sweden (Md 15 years, range 1–44) and in their home country. In general they had rather long experience of psychiatric care.

Table 2. Country of birth among the 126 informants in the four studies.

Country of birth	No.
Scandinavian countries	
Sweden	68
Finland	3
Other European countries	
Former Yugoslavia	18
Turkey	5
Poland	2
Hungary	2
Germany	1
Syria	1
Non-European countries	
Vietnam	3
Chile	3
Afghanistan	2
Egypt	2
Iran	2
Iraq	2
China	2
Unknown	2
Israel	1
Philippines	1
Argentina	1
USA	1
Somalia	1
Palestine	1
Uganda	1
Nigeria	1
Total	**126**

Selection of informants

Staff (I) consists of nurses and assistant nurses working in psychiatric and somatic emergency care with at least two years' experience in the area. The limit of two years was set in order to ensure that the informants had broad experience of encounters with foreign-born persons.

As perceptions are based on experiences in reality (Marton & Booth 1997) the informants involve foreign- and Swedish-born persons diagnosed with psychosis (II) and families of persons with psychosis (III) at a psychosis outpatient clinic. Informants were recruited to the study by health care staff working at a psychosis outpatient clinic. Excluded from the study were persons with organic psychoses and persons with an ongoing acute psychosis (Socialstyrelsen 2005). In order to exclude those people, the contact person at the psychosis clinic made an assessment and those showing early signs of relapse (RFS 1998) at the time of the interview were not invited to participate.

One of the most important things when using the Delphi technique is to clearly define the sample of experts (Broomfield & Humphris 2001). Expert status (IV) meant having particular knowledge of psychosis care as health care staff working in psychosis care, being foreign-born having a psychotic diagnoses (II) or being a family member of a foreign-born person with a psychotic diagnoses (III). Experts were recruited from psychosis outpatient clinics all over in Sweden and included both women and men of different ages with varying professional experience and education, being here voluntarily or involuntarily with a residence permit in Sweden.

Data collection

In order to explore perceptions, the preferred method of data generating is the semi-structured interview (Krueger 2009; Marton & Booth 1997). The focus group interviews (I) were performed during November–December 2003 while the individual interviews (II–III) were conducted from August 2005 to February 2006. All interviews were performed following semi-structured interview guides. The Delphi technique was applied from February 2008 to February 2009 and data was collected by questionnaires.

Focus group interviews

The first focus group was a pilot test (included in the study). The focus group interviews were led by a moderator. The strength of focus group interviews is that informants often appear creative, dynamic, lively, and in the group discussions when persons feel secure they get carried away in the discussion and thoughts and experiences, even unconscious ones, are uncovered (Krueger & Casey 2000; Krueger 2009). Disadvantages of focus groups are that the informants may influence each other or try to impress each other. Some informants appear to be smart or clever while others may appear quiet and withdraw (Krueger 1998b; Krueger 2009). To avoid those situations, a facilitator participated in all group interviews. The facilitator noted and reflected on the group dynamics, and in one of the interviews the facilitator discovered that the group had misunderstood the aim of the study, so this was discussed and then it was no longer a problem. Through focus group interviews it was easy to illustrate similarities and dissimilarities between staff working in somatic and psychiatric care. Each focus group interview took 1.5–

2 h in free-flowing discussions following a semi-structured interview guide The interview guide was based on the main aim: to describe as carefully as possible problematic situations when caring for foreign-born persons.

Individual interviews

The individual interview (I–II) was used as it appeared difficult to hold a focus group interview with persons from different countries, speaking different languages and diagnosed with different psychotic diagnoses. The interview guides used in studies II and III were the same but from the perspective of the person with psychosis or the family. The guide was based on the national guidelines of support to families of persons with psychosis (Socialstyrelsen 2003) and included four open-ended questions concerning perceptions of psychosis care, encounters with health care staff, information received and involvement in care. To develop a relaxed atmosphere the informants were allowed to select the place for the interview. Two pilot interviews (included in the study) were carried out in both studies. In study II this led to the addition of the question, What psychiatric care have you received?

The interviews (II–III) took between 35 minutes and 1.5 hours. All informants communicated in Swedish, except one person in study II. This person received information translated into the relevant language and the interview was performed with an authorized interpreter who used the sequential translation technique (word by word). Communication in all the interviews was unproblematic and free flowing.

Questionnaires

First round

In the first round the results of three previous studies (I-III) consisting of perceptions of psychosis care from the perspectives of those involved in psychosis care were reformulated to generate 39 statements which were structured in a questionnaire (Bond & Bond 1982). To limit communication misunderstandings, the questionnaire was tested on six "experts" – persons with psychosis, families and staff from different countries – and led to clarification and revision of the statements. After the revision was made the experts were asked to give feedback about the content of the statements once more.

Second round

In the second round the questionnaire with the statements was sent out, and the experts were asked to rate their level of agreement with these (not important at all, less important, important, very important).

Third round

The third round was based solely on results from the second round. Those statements on which agreement was reached in the second round were taken away from the questionnaire and those statements added by the experts in the second round were added to the questionnaire. The questionnaire was tested with three "experts" (foreign-born persons) and led to no changes. The tests were not included in the study. In this third round the experts received information about their own and the group's ranking of the statements. They were asked to rate the level of importance of the statements about which

agreement was not reached in the second round as well as those statements added by the experts in the second round (Murphy et al 1998).

Data analyses

All interviews (I–III) were audio-taped and half were transcribed by the author herself and the rest by a professional secretary. The transcripts were coded with the time and place of the interview, the name of the interviewer and country of birth of the informants. The tapes and the transcriptions were marked with the same coding and kept in a locked cabinet accessed only by the author. Immediately after each interview memos were written down in a diary to capture thoughts about what had appeared during the interview (Patton 2002). All tapes were listened to in order to make sure that the interviews were correctly transcribed. Thereafter the interviews were read several times in order to identify statements relevant to the aim of the study.

Focus group analyses

The focus group interviews were analysed according to the method described by Krueger (1998c). Data collection and analyses of data proceeded simultaneously and the principle of saturation guided the study. Thus, the analyses proceeded until no new information emerged. Three focus groups in general need to be held within each area before saturation is reached. The texts were analysed independently and compared by two persons, showing high agreement in the development of categories. All opinions connected to the informants' experiences of encounters with foreign-born people were marked with a highlighter and memoranda were written in the margin. Words and

opinions with similar meanings were brought together in subcategories. Comparisons were made during the whole analysis between the subcategories and the text as a whole. Different subcategories were shaped, and when no new interpretations of the text appeared, the subcategories with similar meaning were brought together into main categories. The main categories were shaped on the basis of differences in the subcategories in such a way that they are distinguished from each other. The names given to the categories are as close to the terms in the original text as possible and sum up the meaning of the category. The aim of the analysis was to discover regularities, contradictions, patterns and themes in the text (Krueger & Casey 2000).

Phenomenographic analyses

Data from the individual semi-structured interviews were analysed by the principle of phenomenographic analysis described by Sjöström and Dahlgren (2002). Familiarization is the first step in which the researcher is introduced to the empirical material by reading through the transcripts and correcting any errors in the transcript. The second step involves compilation of answers from all informants to identify the most significant elements in answer given, after which a condensation of the individual answers to find the central parts of longer answers is done. Next a preliminary grouping or classification of similar answers was made before the preliminary comparison of the categories. Establishing borders between the categories sometimes entails revisions of the preliminary groups. The categories were named to emphasize the essence, after which a contrastive comparison of categories was made, which involves a description of the unique character of each category and a

description of resemblances between categories, resulting in what is called the outcome space.

Different perceptions can be related alongside each other (horizontally), or they can form a hierarchical system in which perceptions are not just sidelined but also subordinate to each other. One fundamental requirement is that the perceptions are related to the same phenomenon (Marton & Booth 2000). Otherwise there is a chance of making a descriptive content analysis an account of the fact that different conditions or phenomenon are mentioned in the interviews and the axis around which the perceptions are centred is missing (Uljens 1989). In study II the categories were related horizontally as none of the perceptions could be seen as having more dimensions than the others (Marton & Booth 2000). In study III it was found that the two categories "attitudes to psychoses" and "taking responsibility" were dependent on the category "access to care", so there was a hierarchical order of the descriptive categories in the outcome space.

Statistical analyses

The ranking of the statements in the Delphi technique was analysed and calculated using descriptive statistics. The level of agreement was defined when 50% of the experts scored the same ranking (not important at all, less important, important, very important) on a statement (Powell, 2003). Ascertaining whether statements about which agreement was reached tended towards unimportant or important, those variables were dichotomized (Altman, 1991). A demand for 80% agreement in either direction was set.

Any response items with a score less than those percentages were included in the third round. The statements with disagreement after the third round were studied separately as they seemed to be of major interest, since they illustrate situations where difficulties may develop in the care of foreign-born persons with psychosis. The experts were treated as a homogeneous group for the purpose of analysis, and no comparison within the group of experts was made. Calculations were performed in SPSS 14.0.

Trustworthiness

In all qualitative studies trustworthiness is about being able to describe the research process including the study design, sample of informants, data collection and analyses in a systematic and honest way. The criteria used for trustworthiness in qualitative studies are credibility, transferability, dependability and confirmability (Patton 2002).

Credibility concerns the researchers' ability to communicate the pre-understanding of the researchers as well as the research process, by giving a precise description of each part of the research process (audit-trail), to ensure credibility (I-IV) (Sjöström & Dahlgren 2002). In order to illustrate different perspectives of perceptions of psychiatric care, perceptions were explored from the perspectives on health care staff (study I), persons with psychosis (study II) and the family (study III). This could be seen as a form of triangulation of qualitative data sources (Patton 2002) illuminating a phenomenon from different qualitative perspectives. According to Sjöström and Dahlgren (2002) credibility is enhanced by providing quotations from the interviews, so that the relevance of the categories can be judged. The content

of the categories was double-checked to confirm the relevance of the categories. The credibility of the study is ensured by the way differences and similarities between groups are supported by the empirical material

Transferability is about the researchers' ability to clearly define the population studied and the findings but leaving it up to the reader to decide whether the results can be transferred to another population or not (Patton 2002). The main goal of this thesis was to explore and describe varying ways of understanding a phenomenon, not explaining by generalizing the results. However, carefully collected and analysed qualitative results are transferable to similar groups (Krueger & Casey 2009). According to Marton & Booth (2000) it depends on the extent of variations among individuals in the group studied whether the results are applicable to a larger population. The studied group varied in age, gender, time of residence in Sweden, length of experience of psychiatric care in Sweden, educational level, relation to the person with psychosis, diagnosis and experiences of psychiatric care in the home country. They were staff, persons with psychosis and families. Thus the studied group represents a broad range of experiences, which is the main goal of phenomenographic research (Marton & Booth 2000).

Dependability in qualitative studies is about the quality of technical instruments (Patton 2002) which in studies I, II and III was the tape-recorder. The tape-recorder was used in order to be sure of capturing what was said during the interviews. Dependability is also about the quality of the tapes, as data may be lost if the quality of the tapes is inadequate. The researcher's ability to carry out interviews of good quality also affects the dependability of

the study. This is difficult to describe, but the interviewer in all studies had experience of being a psychiatric nurse working in psychosis care, which could be seen as a strength.

Confirmability is about the researcher being neutral and not colouring the findings with the pre-understanding of the phenomenon studied (Patton 2002). There should be a reasonable degree of agreement where two researchers agree in at least two thirds of the cases when comparing their judgements and where they reach agreement in two thirds of the remaining cases after discussion (Marton & Booth 2000). There was agreement about the content of the categories in all studies and further there was agreement about the content of the categories developed between the researchers involved in analysing the data who had different experiences of health care, areas of research and methodologies, which is also a way to confirm that the results are not coloured by the researcher's pre-understanding and thus can also be seen as a form of investigator triangulation (Patton 2002).

The Delphi technique (IV) has been criticized for having no evidence of reliability. In other words, if the same information was given to two or more panels there is no guarantee that the same results are obtained (Williams and Webb 1974) Other Delphi users have found that the results of a study designed to replicate a Delphi technique 16 years later presented findings which were accurate in terms of forecasting communication developments (Ono & Wedemeyer 1994). Goodman (1987) states that if the panels participating in the study are representative of the group or the area of knowledge, then content validity can be assumed. The expert group in this study consists of those

involved in psychosis care all over Sweden and can be seen as representative of those who have knowledge of psychosis care.

Ethical issues

There are ethical difficulties when studying persons with serious mental disorders. As the informants also are foreign-born and speak other languages, this may cause possible communication difficulties. However, it is important to study vulnerable groups to identify their needs, as a first step to developing a deeper understanding (Senior & Bhopal 1994) but some ethical implications must be taken into consideration This thesis has been conducted in accordance with the principles for human clinical research in the guidelines stated in the World Medical Association Declaration of Helsinki (1996). All informants received written and oral information about the aim and implementation of the study and the voluntary nature of participation, which could be interrupted anytime with no further explanation, and with the assurance that anonymity would be preserved. Written Informed consent was given by all informants. There was no dependent relationship between the informants and the researcher (I–IV). The studies were approved by the Ethics Committee of Lund University LU 643-03 (I) the Ethics Committee of Linköping University, Sweden, No. 13/05 (II–III). To preserve the confidentiality of informants' data, audio-tapes and transcripts were coded by a number and analysis and presentation of data was made in a way that concealed the participant's identity. All collected data was separately stored in a locked space in the principal investigator's office, accessible only to the investigator.

RESULTS

First there will be a presentation of the results that those involved in care agreed as being important. Then there will be a presentation of the perceptions of which there were no agreement.

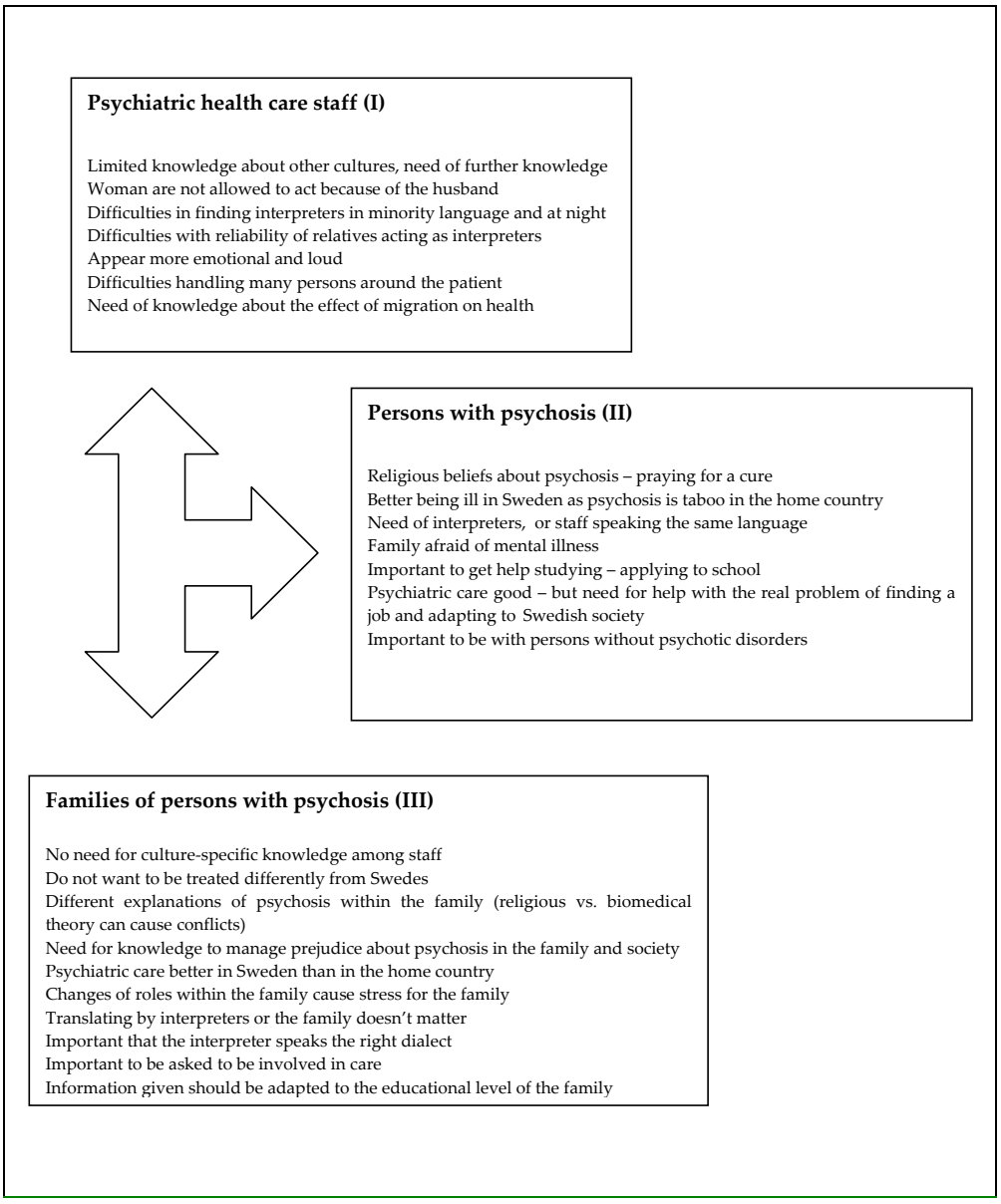
Perceptions were more similar than different between somatic and psychiatric care and between foreign- and Swedish-born persons. The core components found among those involved in care concerned general psychiatric care and can, in broad outline, be said to include: care on equal terms, the importance of relating to staff, being taken seriously and met with respect, communication and information, participating in care, identifying stressors and having something meaningful to do (table 3).

In general psychiatric care there were perceptions that did not reached agreement. Those can, in broad outline, be said to include: Staff´s awareness about how foreign-born persons are affected by previous experiences of migration and different beliefs of psychosis and use of different nonverbal language. Further statements involve changes of family roles and different needs of participation in care and access to an interpreters when assessing the need of care and access to interpreters speaking the right dialect. Figure 2 describes those individual perceptions from the three perspectives studied (figure 2).

Table 3. Overview of the core components and perceptions on which agreement was reached (IV based on I–III).

Core components	**Perceptions on which agreement was reached among those involved in psychosis care (foreign-born persons with psychosis, families and staff)**
Care on equal terms	Families should be treated in the same way irrespective of which country they come from All individuals in care should be treated in the same way irrespective of where they come from
Importance of relating to staff	A patient should meet the same staff if he/she visits psychiatric care regularly The staff should ask what the family expects of the staff The staff should have time for people being cared for on the ward To deal with people from other countries it is more important that the staff have the interest and the will rather than knowledge It is not important that the patient or the family decides whether care should be given by female or male staff
Importance of being taken seriously and met with respect	The staff should respect the fact that people can have different explanations for their psychosis The staff should listen to the family and take them seriously when they seek psychiatric care for a family member The staff should understand that it can be difficult to trust in professional secrecy in Sweden if one comes from a different country The person's religious background is not important The person's ethnic background is not important for care
Importance of communicating and receiving information	It is important that the interpreter who translates is certified (i.e. has special training) There should be enough time for staff and foreign-born families to talk to and understand each other There should be easily available information for everyone about how Swedish health care functions The person receiving care should be given information about psychoses in order to better understand and cope with the illness The family should be given information about psychoses in order to better understand the illness All the information given should be easy to understand
Importance of participating in care	The person receiving care should be able to decide who should participate in the care The person receiving care should be allowed to suggest treatments that have previously worked well The family should be allowed to say how they feel and whether they need support The staff should ask what the family expects of the care The staff should take into consideration how the children in the family feel
Importance of identifying stressors	The staff should find out what causes stress and has a negative effect on the person receiving care The staff should ask about previous traumatic experiences and offer the person help to come to terms with them Previous negative experiences of psychiatric care can lead a person to feel no confidence in psychiatric care today
Importance of having something meaningful to do	Staff should support the person receiving care to get out into some form of work if this is important for him/her The staff should motivate the person in care to do things that make him/her feel well

Figure 2. Perceptions on which agreement was not reached, illustrated from the three perspectives studied (I–III).



Care on equal terms

All those involved in care illustrate the importance of care being given on the same terms to everyone irrespective of country of origin (I–IV).

The importance of relating to staff

Relating to the same person during a long period of time and being asked about one's own expectations of staff were seen as important (I–IV). Relating satisfactorily was a mix of perceptions and involved staff being human, non-professional, professional or authoritarian (II–III). There was agreement that the person with psychosis and the family should not decide whether care should be given by male or female staff (IV).

However, health care staff experienced that foreign-born had different expectations of staff and felt they lacked knowledge about other cultures and how to act when behaviours were perceived as culturally related or if there were many persons around the patient (I). They also found it difficult to handle what was experienced and described as more emotional and loud behaviour (I), even though no agreement could be reached about the importance of staff carrying knowledge of families different explanations of psychosis (IV). The families did not expect health care staff to carry knowledge about specific cultures but plainly explained the importance of being interested in trying to understand each other (III).

Being taken seriously and met with respect

Being respectfully encountered and listened to irrespective of individual perceptions of psychosis and irrespective of country of birth was seen as important (I–III). Asking about the person's religious and ethnic background was not seen as unimportant (IV).

No agreement could be reached about the importance of staff having knowledge about families having religious ideas about psychosis or status of women in different countries, or needing university courses on beliefs about mental illness (IV). Families described how religious strategies to manage the psychosis could cause conflicts, as some of the family members had adopted the biomedical model of explaining diseases used in Sweden while others retained religious explanations (III). This meant that the family used different ways of managing the psychosis. Further, no agreement could be reached about the importance of knowing that psychosis may be taboo in some countries and that some families are ashamed of the illness (II–III).

Communication and information

It was found important to communicate in a proper manner using interpreters (IV). Health care staff described difficulties in not always having access to interpreters (I). When using families as interpreters, staff sometimes doubted the reliability of the translation (I). Among persons with psychosis it was viewed as important to communicate through an interpreter but even better if health care staff knew the language (II). If the person with psychosis had some knowledge of the Swedish language there was a wish not to use interpreters

(II). Families did not mind whether translating was done by an interpreter or by the family. If using interpreters they wanted an interpreter who spoke the right dialect (III).

There was agreement about the importance of knowledge of psychosis for all involved in care (II–III) in order to understand the illness and manage prejudiced attitudes within the family and in society (IV). Easily understood information was regarded as important (I–IV).

Participating in care

There was agreement about the importance of the person with psychosis deciding who should participate in the care and the importance of resuming treatment that had good effect in the home country (IV). The families should be asked about their expectations of care and whether they need support from health care staff (IV).

No agreement was found about the importance of asking the families to participate in care or ask them about how they support each other within the family (IV). Families described taking responsibility for the patient and demanding more of psychiatric care, as this reduced the stress level of the family (III). Foreign-born persons perceived compulsory treatment as helpful (II).

Identifying stressors

Core components involve knowing that previous negative experiences of care can have a negative influence on a person's confidence in current care. It was seen as important to identify and offer treatment to those suffering from post-traumatic stress syndrome (IV). No agreement could be reached about the importance of staff knowing how migration may affect the person's health (IV). Health care staff found it difficult to handle persons suffering from post-traumatic stress syndromes as the condition requires a certain kind of treatment (I).

Having something meaningful to do

Helping the person with psychosis to find a job or support him/her to do things affecting mental health in a positive manner was seen as important (IV).

The families found it hopeful to have opportunities to study when having a psychotic disorder in Sweden (III). Even though the importance of social factors was mentioned in all studies (I–III), no agreement was found about the importance of social support in order to go to school or become established in Sweden (IV).

DISCUSSION

Methodological considerations

It could be discussed whether there is a risk in classifying all foreign-born persons as a homogeneous group and separating them from Swedes. This was not the aim of the thesis as there is no intention to develop a theory describing differences in attitudes among all foreign-born persons but instead to illustrate different perceptions among foreign-born persons receiving psychosis care on the same terms.

Perceptions of staff from the social services are not included in the studies. Even though the aim was to identify perceptions of hospital outpatient psychosis care the results illustrate that support from other institutions than outpatient care, were important for the well-being of persons with psychosis and their families, such as the need to meet persons with no psychosis, the need for a job, the need to be integrated in Sweden, which is the responsibility of the social services (SFS 1993; SFS 2001). However, there was no scope to involve further informants in the studies, but this need to be done in future studies.

The first studies begin by identifying individual perceptions on local levels (I–III). In study IV we turned to psychosis outpatient clinics on a national level in Sweden in order to capture the wider perspectives of psychosis care.

The educational level differed between staff (I) working in somatic care (mainly nurses with higher education) and psychiatric care (mainly assistant nurses with no higher education), which may be due to the different requirements of educational level among staff in different fields.

Among the foreign-born persons (II) one had been treated for psychosis in the home country and four had a family member who had been treated for psychiatric problems in the home country, while the rest developed their psychosis 5–10 years after arrival in Sweden, which is similar to what other studies have found, that the rates of psychosis are higher among those who have been in the country for 10–12 years (Bhugra 2004). The informants had been in Sweden a rather long time, and thus have long experience of psychiatric care, which influences their perceptions of psychiatric care, which are a more Swedish perspective. However, this is the reality and the reality is what we aim to describe.

The families (III) were recruited to the study by health care staff at the clinic after approval from the patients was obtained. Therefore, it is possible that the families of those that were most suspicious or paranoid and those not aware of their psychotic illness were not asked to participate. In order to capture their perceptions family members would have to be invited without approval from the patients.

A risk of the procedure of sending statements back and forth, as done with the Delphi technique (IV) is that the experts can feel pressured to agree with the opinion that is hold by the majority of the group (Murphy et al 1998).

However, the strength of the Delphi technique is the anonymity among the experts, which gives them the possibility to really state their point of view on the subject without feeling pressure from other experts. Since the opinions of the expert groups were given independently and since they were not known to each other, the bias was eliminated (Keeney et al 2001).

As few "Delphi" researchers report testing the statements before implementation, it is unclear how many tests should be undertaken. Should there be one for every round or only one for the initial round (Keeney et al 2001)? In this study one pilot test of six experts was made in the second round and one test with three persons in the third round.

Who should be included in a group of experts may be questioned, and there are also questions about the composition of the group (Reid 1988). For example, what type of informants there should be is related to the question of what an expert is (Murphy et al 1998). Depending on the research area, the expert could be a clinical expert, a scientific expert or an expert through experience of the area under investigation. In some studies the panel might have to consist of experts from all three areas (Murphy et al 1998) as in this study, which is a clear strength of the study.

It could be discussed whether the Delphi technique was the most suitable method for studying foreign-born persons with psychosis and their families. Problems experienced in this study included the difficulty of recruiting experts through others due to matters of confidentiality. Reasons stated by health care staff for not being able to recruit experts were said to be limited numbers of

foreign-born persons with psychosis, lack of interest in participating and limited time. However, 43 experts were recruited and the quality of the experts and their opinions is viewed as a strength of the technique and more important than its numbers (Powell 2003). The Delphi technique can be implemented through e-mailed questionnaires, private decision making or group discussions (Murphy et al 1998). E-mailed questionnaires seemed difficult as this requires that all informants have access to computers and can manage e-mail, which could be seen as a large demand on the population studied. Conducting individual interviews did not seem to bring new other perspectives than those found in the first three studies of the dissertation (I–III). Conducting group discussion with persons suffering from different psychotic disorders, of foreign birth and with different languages seemed like a difficult undertaking. Furthermore, the long distances between those choosing to participate made group interviews very impractical.

The benefits of combining different methods (method triangulation) with different perspectives on a phenomenon include the greater chance to capture the overall picture and to overcome the bias that comes from single methods (Patton 2002). The main goal of this thesis was not to generalize the results. However, a range of variation among individuals in the group is important to make the results transferable to a group of people similar in characteristics (Marton & Booth 2000). The data were collected and analysed in such a way that the qualitative findings are transferable to similar groups. As foreign-born persons as well as persons with psychotic disorders are at high risk of developing somatic problems (Filik et al 2006) there is a possibility to encounter them in all kinds of health care and thus the results can be useful in

other areas than psychosis care. Furthermore, perceptions of staff in somatic emergency care did not differ very much from the perceptions of staff in psychiatric care, so the results could also be useful in somatic emergency care.

There is always a threat to transferability when conducting interviews with persons using different languages (Kapborg & Berterö 2002). Different words in different languages express different realities, and some words cannot be translated, making it difficult to translate and understand correctly what the person is saying (Patton 2002). Therefore all informants were offered the use of an interpreter in the interviews and when answering the statements. However, only one participant wanted help to translate, and for that interview a certified interpreter with experience of psychosis care was engaged. The use of an interpreter, as well as the decision not to use an interpreter when needed, can cause problems in the validity of the interviews (Kapborg & Berterö 2002). The risks must be weighed against the consequences of missing data from foreign-born persons, which seemed inappropriate concerning the aim of the study.

Discussion of results

This thesis is unique as it describes perceptions of psychosis care among those involved in psychosis care, and further on the basis of the results identifying core components in the care of foreign-born persons with psychosis and their families. The main findings were that psychiatric general care was seen as the most important from all the perspectives studied. The core components are based on the guidelines developed by the Socialstyrelsen (2003) and indicate that these show the general direction for giving care to foreign-born persons with psychosis and their families. However, within the core components there

were perceptions about whose importance those involved in care did not agree about. This illustrates that further development of psychosis care is needed to identify and meet those individual needs.

Care on equal terms

Irrespective of country of origin and demographic background (gender, age) there was agreement that all persons with psychosis should be cared for on equal terms, as is also declared by Leininger (2006). However, when encountering foreign-born persons it is easier to pay attention to dissimilarities and overlook similarities, and thus distance them from ourselves (Olsson 2007). It is easy to assume established prejudices when encountering foreign-born persons and see the person as a representative of the culture instead of an individual (Fereshteh 2008). In order to give general psychiatric care on equal terms, staff need to identify individual perceptions, which may require basic cultural competence (Leininger 2006). There are frameworks to use for health care staff, e.g. that of Giger and Davidhizar (2004), to identify cultural phenomena that vary among cultural groups and therefore are important to explore. Leininger (2006) describes phenomena which affect the output of care and therefore should be explored in order to give individual-based care. It is nevertheless demonstrated that nurses lack the competence to care for foreign-born persons (Wamala et al 2007). This is partly explained as practising nurses' find the conceptual frameworks difficult to apply to their everyday practice (Jirwe 2009).

The importance of relating to staff

In this dissertation perceptions of relating to staff clearly illustrate the patient–staff relationship as important for positive caring. Among inpatients in psychiatric hospitals in London relationships with effective communication and culture sensitivity resulted in the person gaining a sense of trust (Gilburt et al 2008). The results of this study further illustrate the importance of staff not only being professionals but also human beings; this resulted in a sense of trust for some, while others expected health care staff to be the experts telling them what to do, with no further desire to be involved in psychiatric care. A positive authoritarian impression given by health care staff can be perceived as powerful, giving hope of recovery to the patient (Sachs 1992). Staff experienced limited knowledge in encountering foreign-born persons in a good manner, while families find the will and interest to understand each other more important than cultural knowledge among staff. In other studies they assume that it may improve the cultural encounters if health care staff are prepared with competence, knowledge and skills relevant to their practical nursing (Leininger 2006; Colley 2003). Situations experienced as difficult by staff also need to be illustrated. Clinical guidelines could be useful to help foreign-born persons to understand why health care staff act the way they do to prevent discriminating thoughts and to be aware of the relation, which is seen as a decisive factor in maintaining treatment with these often poorly motivated psychotic persons (Socialstyrelsen 2003; Arvidsson & Arvidsson 2005). Health care staff raised the difficulties of foreign-born persons' desires to be cared for by either male or female staff, while this was not important from the perspectives of the person with psychosis and the families. Leininger (2006) and Giger and Davidhizar (2004) do not discuss this aspect of caring.

Nor do they give suggestions about how to handle situations when staff, the person with psychosis and the families do not agree. Further exploration of these aspects is needed.

The importance of being taken seriously and met with respect

Being taken seriously was important in this dissertation yet malingering was mentioned by all the groups of informants. Health care staff illustrated perceptions of foreign-born persons faking illness in order to receive psychiatric care; families describe how the foreign-born person has been accused of malingering when they have had a really difficult situation, not knowing how to handle the psychotic person. Malingering described from the three perspectives could be seen as misunderstandings rather than malingering behaviour. As mentioned by Qureshi et al (2008), perhaps the greatest challenge in cultural competence training involves the development of attitudinal competence in as much as it requires exploration of cultural and racial preconceptions.

Beliefs about mental illness may differ between persons from different ethnic backgrounds (Kleinman 1980), and according to Leininger (2006) as well as those working with cultural adaptation programmes (Weisman et al 2003; Snyder et al 2004; Rosenfarb et al 2004) this is important to take into consideration in care. This was not what was described by informants in this thesis. Instead those involved in psychosis care agreed that religious and ethnic perspectives were not important to consider in psychosis care. However, it was viewed as important to know that psychosis is taboo in many countries. According to Hanssen (2006) it is easy to take the own personal

customs, ideas and behaviours for granted and consider them as the "correct" way to think and act. Only after exposure to persons from different cultures are we aware of the fact that there are different opinions about the "correct" thoughts, ideas and acts (Leininger 2006). No agreement could be reached concerning different ways of managing the psychosis. However, a treatment strategy consistent with the patients' and the families' beliefs may have a better chance of being successful, and therefore their reactions to psychosis and ways of managing the illness need to be incorporated in treatment strategies (Giger & Davidhizar 2004). The individual ways of managing psychosis should not be seen as a contrast but as a complement to Western psychiatric care (Rousseau 2005).

Communication and information

Communication and need of interpreters is illustrated in all four studies in this dissertation. Different perceptions concerned translating by certified interpreters or the family. From the staff's point of view it was difficult to trust the reliability of family members translating. According to Lindert et al (2008) it is impossible to translate medical or everyday concepts of disease and treatment properly into a different language without considering the connotations and implications of each term as it relates to the respective culture. Terms that are central to Western medical models of disease may otherwise be misunderstood, misinterpreted or simply rejected, which of course must be taken into consideration when communicating through interpreters as well as families. There are always practical issues making it difficult to practise perfect care, and a problem found in this study was access to interpreters. This question must be highlighted and discussed at each clinic

as health care staff must be able to communicate in order to form an opinion about the correct individual treatment (Leininger 2006). According to the Health and Medical Services Act (SFS 1982:763), care should be given on the same terms to everyone. Other findings illustrate the importance of having certified interpreters who do not know the family and speak the right dialect. However, no agreement was reached about the importance of these issues. All the perspectives studied illustrate the importance of receiving information about the psychosis in order to manage prejudiced attitudes within the family and society. Even though foreign-born persons perceived it as better being psychotic in Sweden, they were affected by negative prejudice in society. Even though families of persons with psychosis in studies brought up their needs of more support from mental health professionals and the community in combating stigma against mental illness (Jakob et al 2007; Foldemo et al 2003), this is difficult for staff to influence. The results of this as well as other studies indicate that society needs information and knowledge in order to develop an understanding of psychotic disorders.

Participating in care

There was agreement about the importance of the person with psychosis being the one to decide who should participate in care and having possibilities to suggest treatments that have previously worked well. Leininger (2006) states that it is important that the nurse take into consideration both the emic (patient's) perspective and the etic perspective (that of outsiders, family, nurse, physicians). However, in this study there was no agreement about the importance of the families being involved in care, which illustrates that problems may arise in care if the person with psychosis and the family have

different opinions of participation. This is difficult for health care staff to prevent, and according to Leininger et al (2006) and Giger & Davidhizar (2004) it is important to find out about the family roles in order to co-operate and not offend the family members. However, when no agreement is reached among those involved in psychosis care, the Swedish Health and Medical Services Act (SFS 1982:763) state that care is to be given with respect for the patient's right of self-determination and integrity.

Identifying stressors

Post-traumatic stress syndrome is a reaction to a traumatic situation (Socialstyrelsen 2005) which if untreated can lead to lifelong serious health problems (Ekblad et al 2000). The tendency of suicide is higher among those with PTSD (Khan et al 2002), so the condition needs to be treated by professionals (Cullberg 2005), which was also seen as important in the results in this thesis. Foreign-born persons described different expectations of psychiatric care due to negative experiences of psychiatric care in the home country. They either had difficulties trusting psychosis care or had a mainly positive picture of psychiatric care in Sweden. Therefore it is important that staff ask about the patient's previous experiences in order to understand his or her situation (Andén et al 2005).

Having something meaningful to do

Support from other institutions than psychiatric care was mentioned as being important to adopt in Sweden; this has been accomplished in Britain, where it was found that adolescents who had integrated and had friends cross-

culturally had fewer mental health problems (Bhui et al 2005). This illustrates the importance of not medicalizing social problems. Even though the mental health reforms aimed to improve the conditions of persons with psychotic disorders, there are still barriers between social services and psychiatric hospitals which involve psychotic persons having difficulties to access the support needed (Stefansson & Hansson 2001, SOU 2006).

However, even though the importance of social needs was illustrated by persons with psychosis, families and health care staff, there was only agreement of the importance of helping the person to find a job but not about helping the persons to meet others without psychosis or to apply for education. Maybe the explanation for this is that social needs are the responsibility of the community services and not the psychiatric hospital (SFS 1982:763; SFS 1991), so these statements were not seen as concerning the duties of staff at the psychiatric hospital. When comparing unmet needs among persons with psychosis it was found that foreign-born persons had more unmet needs concerning accommodation as well as basic education and economy than the natives (Arvidsson & Hultsjö in press), which indicates that this area should be further explored in order to develop possibilities for foreign-born persons to have a meaningful existence despite suffering from a psychotic disorder in a new country.

Conclusions

Perceptions among staff in somatic and psychiatric care as well as among foreign- and Swedish-born persons with psychosis and their families showed

more similarities than differences. General psychiatric care is important for Swedish-born as well as foreign-born persons with psychosis and their families. However, within the general psychiatric care different perceptions were found. Those involved in care did not agree about the importance of those different perceptions, which indicates that further development is needed to arrange psychosis care in a way that is satisfactory for all those involved. The development suggested is to highlight the importance of identifying individual perceptions which are culturally determined and to help staff to acquire strategies so they can easily manage to encounter and offer general psychiatric care to foreign-born persons in order to meet their individual needs. Development must take place on an organizational level and on an individual level.

Clinical implications

The core components in care were identified by those involved in care as general psychiatric care. Therefore, nurses should be encouraged to focus on the general psychiatric care irrespective of who they meet. The guidelines from the Socialstyrelsen (2003) entitled "Care and support for patients with schizophrenia in Sweden" could be suitable to use as the platform for care. As different perceptions exist and they may or may not be determined by the cultural background, it is important that staff assess individual perceptions. Staff could be guided in the discussion if they start by asking a few basic questions concerning

- Satisfactory ways of relating to and communicating with staff.
- The patient's as well as the family's need to participate in care

- The patient's and the family's ways of managing the psychosis
- Identifying previous experiences of psychosis and psychiatric care as well as previous traumatic experiences
- Identifying perceptions of support in order to adapt to Swedish society
- Identifying meaningful activities for the person

It is important not to see foreign-born persons as a carrier of a culture but as an individual with his/her own perception. In order to make staff feel secure in encountering and communicating with foreign-born persons there is need for development of psychiatric care on an organizational level and on an individual level. To identify the needs of development, one possible way could be to make a creative atmosphere for health care staff to discuss situations arising when caring for foreign-born persons.

SAMMANFATTNING PÅ SVENSKA

Syftet med denna avhandling var att beskriva och analysera uppfattningar av psykosvård bland personer involverade i vården (utlandsfödda och svenskfödda personer med psykos, utlandsfödda och svenskfödda familjemedlemmar till personer med psykos samt vårdpersonal). Vidare syftade avhandlingen till att utlandsfödda personer involverade i psykosvård runt om i Sverige skulle nå enighet om huvudkomponenterna i psykosvård. Detta för att identifiera om rådande psykovård är lämplig för utlandsfödda personer med psykos och deras familjer.

Studiedesignen var explorativ och beskrivande. Vårdpersonal (35 st), personer med psykos (22 st) och familjemedlemmar (26 st) till personer med psykos var tillfrågade från olika län i Södra Sverige. För att fånga vårdpersonalens erfarenheter och utforska om specifika behov förelåg i psykiatrisk vård genomfördes nio fokusgruppsintervjuer. Individuella intervjuer genomfördes för att utforska och fånga personer med psykos (22 st) och familjers (26 st) uppfattningar av psykosvård. Slutligen, genomfördes en studie på nationell nivå i Sverige i vilken utlandsfödda personer med psykos, familjer till personer med psykos och vårdpersonal fick besvara ett frågeformulär i flera omgångar för att identifiera och enas om vilka huvudkomponenterna är i vård till utlandsfödda personer med psykos och deras familjer.

Det fanns en enighet om att huvudkomponenterna i psykosvård är den generella psykiatriska vården (I–III). Att låta en person välja om vård ska ges av kvinnlig eller manlig personal likväl som att fråga om personens etniska och religiösa bakgrund sågs som mindre viktigt.

Ingen enighet kunde nås om uppfattningar som rörde olika förklaringar till psykossjukdomar, behandlingar och olika sätt att hantera sjukdomen. Inte heller kunde enighet nås om huruvida personal behöver specifik kulturell kunskap eller om tolkar ska prata specifika dialekter och vara okända av familjen.

Uppfattningar bland personal inom somatisk såväl som psykiatrisk vård och bland utlandsfödda såväl som svenskfödda var mer lika än olika. Generell psykiatrisk vård är viktigt för utlandsfödda såväl som svenskfödda och indicerar vikten av att inte låta kulturellt bestämda uppfattningar förespråka vårdhandlingar och ta energi från personal så att de förlorar fokus på de grundläggande faktorerna i generell psykiatrisk vård. Inom den grundläggande psykiatriska vården fanns uppfattningar om vilkas viktighet ingen enighet nåddes. Vidare utveckling av psykosvård är föreslagen för att belysa vikten av att identifiera individuella uppfattningar som varierar mellan personer och är färgade av personens kulturella bakgrund. Personalen behöver strategier och metoder för att lätt kunna bemöta utlandsfödda personer vilket är en förutsättning för att kunna erbjuda generell psykiatrisk vård. En utveckling av psykosvård måste ske både på en individuell, och en organisatorisk nivå.

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