

# KARIN INGVARSDOTTER

## MENTAL ILL HEALTH AND DIVERSITY

Researching human suffering and resilience in a multicultural context





## MENTAL ILL HEALTH AND DIVERSITY

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**AND DIVERSITY**

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Malmö University, 2011  
Faculty of Health and Society

The happiest people don't necessarily have the best of everything;  
they just make the best of everything they have.

(Unknown)

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# ABSTRACT

The general objective of this dissertation was to study the putative underutilisation of mental health services in a multicultural context. The method followed a qualitative interview-based naturalistic approach, and the interview format was primarily semi-structured. Special attention in the method section has been given to the role of the interpreter in research.

For some time the research areas of underutilisation of mental health care among immigrants, and that of children of immigrant parents suffering from mental illness, have been dominated by a vulnerability approach. Results from the present thesis show that this one-dimensional picture of immigrants as a category associated with psychopathology ought to be balanced with that of strength and resilience.

It was also found in the studied group that underutilisation of mental health care is partly due to the perception of mental conditions as normal life crises, rather than illnesses. Thus, instead of focusing on health care resources, interviewees conveyed their need for greater social and financial support.

The results of this study suggest that there is a lack of extended possibilities, for both adults and children of immigrant background, to express their own needs outside a predefined context. Investigating aspects of resilience in future research on mental ill health in multicultural contexts would challenge the focus on vulnerability, and perhaps so promote resilience.

## ORIGINAL PAPERS

- I. Ingvarsdotter K, Johnsdotter S, Östman M. (2010) Normal life crises and insanity – mental illness contextualized. *European Journal of Social Work*, *in press*
- II. Ingvarsdotter K, Johnsdotter S, Östman M. (2010) Lost in interpretation: the use of interpreters in research on mental ill health. *International Journal of Social Psychiatry* doi:10.1177/0020764010382693
- III. Ingvarsdotter K, Johnsdotter S, Afzelius M, Östman M. The experiences of immigrant children living with parents suffering from mental illness. *Submitted*
- IV. Ingvarsdotter K, Johnsdotter S, Östman M. Underutilisation and hidden resilience. An additional perspective to the understanding of underutilisation of mental health care among immigrants. *Submitted*

All papers have been reprinted with kind permission from the publishers. The data collection and analysis for the first and the second study were carried out by the first author. Data collection for the third study was performed by the first and third author together. All manuscripts were written with support from co-authors.

# INTRODUCTION

As a result of continuing mass migration on a global scale, societies are becoming more and more multi-ethnic. International migration implies a challenge for systems of welfare, something especially visible in the area of mental health care. It also entails a challenge for immigrants, who end up in a new society where values, classifications systems, and institutional organizations may be considerably different than what they left behind in their country of origin. The aim of the present thesis was to study the putative underutilisation of mental health services in a multicultural context.

The origin of the study was a survey showing that people in the multicultural borough of Rosengård in Malmö, Sweden, underutilised mental health services in relation to estimated needs.

The research process has been a journey that started in the country of suffering and mental distress, and ended in a place radiating strength and resilience.

The aim of the first study was to explore perceptions of mental ill health in Rosengård in order to suggest possible reasons why people in the specific borough underutilise mental health care. While empirical data was being gathered, the idea for the second study was born. We realised that something was happening in conversations with informants when an interpreter was involved in the interview and decided to further investigate those issues as a topic in its own right.

In the interviews for the first study, indications appeared that people worried about the children in the area. Based on those voices and a need to investigate a hitherto unexplored area, the third study inquired into the situation of immigrant children living with parents who suffered from mental illness. Finally, results from the first and the third study led to a forth paper on theoretical aspects of underutilisation of mental health care and resilience.

# BACKGROUND

## Utilisation

Low utilisation of mental health services among immigrants in the West is a topic that has attracted cross-disciplinary interest worldwide. Most studies are based on the supposition that there is higher prevalence of common mental disorders among migrant groups and thus increased need for psychiatric care (Fassaert et al., 2009). The mental morbidity among immigrants has drawn considerable attention in psychiatric and epidemiological research, and today there is clear evidence that certain immigrant groups have a higher rate of schizophrenia. It is also established that migration constitutes to be an important risk factor (Bhugra & Jones, 2001; Cantor-Graae & Selten, 2005; Kinzie, 2006). The risk is high when sending and receiving countries are dissimilar such as Caribbean migrants to the UK (Bhugra et al., 1997; Harrison et al., 1997), and Morocco and Surinam to the Netherlands (de Wit et al., 2008; Selten, Slaets, & Kahn, 1997); but low when sending and receiving countries are similar (Kinzie, 2006). The higher prevalence of schizophrenia among immigrants also seems to correlate with studies investigating hospitalization for mental disorders in the same group. In a Swedish four-year cohort study among second generation adult immigrants, it was found that this group had a higher risk of being hospitalized, but only for psychotic disorders (Leão, Sundquist, Johansson, Johansson, & Sundquist, 2005). Regarding the association of non-psychotic disorders and migration, studies have shown contradictory findings (Bhugra, 2004; Kinzie, 2006; Lindert, Schouler-Ocak, Heinz, & Priebe, 2008). In some populations, the prevalence of certain mental disorders has shown to be higher compared to non-immigrants (Bhugra, 2004; de Wit et al., 2008). Other studies have shown that immigrants have about the same risk of developing mental disorders as people in the receiving country (Bhugra & Jones, 2001; Ortega, Rosenheck, Alegra, & Desai, 2000).

The basic idea of utilisation research is that, due to their circumstances, immigrants are vulnerable and have greater needs for mental health services. However, they utilise less mental health care than expected due to various barriers. The objective of many studies is to suggest suitable measures to meet the mental health needs of a heterogeneous population. There are examples of small-scale studies on Arabs and Asian groups in Australia (Wynaden et al., 2005; Youssef & Deane, 2006), Somalis, Ethiopians and Latinos in the US (Ellis et al., 2010; Fenta, Hyman, & Noh, 2006; Kouyoumdjian, Zamboanga, & Hansen, 2003), and immigrants with diverse ethnic and cultural background in the US and Europe (Johnsdotter, Ingvarsdotter, Östman, & Carlbom, 2011; Reitmanova & Gustavsson, 2009). Scholars have also investigated this issue in larger studies, often with mixed methods and epidemiological elements (Kirmayer, Galbaud du Fort, Young, Weinfeld, & Lasry, 1996; Vega, Kolody, Aguilar-Gaxiola, & Catalano, 1999; Östman, 2008b).

The general conclusions of most studies are that immigrants in the West underutilise mental health service which may be due to shame and stigma, inadequate health care resources, lack of information, language barriers, and because they have access to alternative supportive resources, such as religion and social networks.

In several articles low utilisation is concluded by reference to other studies comparing service use between minorities and the host population (Kouyoumdjian et al., 2003; Wynaden et al., 2005; Youssef & Deane, 2006). Such comparisons are rarely adjusted for cultural differences, which implies that all people have the same need for mental health services. Another approach has sought to determine need through the use of specific instruments, such as the Jarman index (Aoun, Pennebaker, & Wood, 2004; Jarman, 1983). The method is based upon the idea that health care resources should be distributed to different areas according to specific social indicators, such as children under 5 years of age, one-parent families, uneducated labourers, the unemployed, immigrants, movement frequency, and overcrowded housing conditions. The Jarman index (also known as the Underprivileged Area Score or UPA), has been exposed to critiques on several grounds, including its indicators. Moreover, the instrument was developed for health care needs in general and not for mental health care in particular. (McCrone, Thornicroft, Boyle, Knapp, & Aziz, 2006; Smith, 1991; Talbot, 1991). One of the key problem in utilisation research seem to be the gap between estimated and perceived needs in study populations (Aoun et al., 2004). The present thesis derives from a survey done in 2005 exploring utilisation of mental health services in Malmö (Senior Partners, 2005). The result of the survey

showed that the population of the multicultural borough of Rosengård utilised considerably less mental health services in relation to estimated needs compared to the rest of Malmö. The study estimated needs by use of the Jarman index. In an international perspective, Rosengård is not unique in having residents with low utilisation of mental health care.

### **Mental ill health, illness, and disorders**

There are many terms describing the absence of mental health: mental illness, mental disorder, mental disability, mental impairment, mental disease, mental ill health, etc., and they all seem to be used differently by various authors and in different contexts. Not only do various languages have different terms, but the words also symbolize different communities and, as Nordenfelt (2000) points out, “health, Gesundheit, santé, and hälsa are not exact synonyms” (p. 108). Presumably the same is true regarding meanings of mental illness.

Even in the field of Western medicine there is no consensus regarding the different terms of mental ill health. It gets even more complicated using them in a multicultural context (Insel & Wang, 2010; Kleinman, 1991; Martinez-Hernández, 2000; Tengel, 2001). Traditionally, researchers have made a conceptual distinction between disease and illness, whereby disease is a pathological process and illness the subjective experience of it (Boorse, 1977; Helman, 2007; Kleinman, 1991; Ottosson, 2000). This division also represents how mental disorders have been studied over time, that is how the brain works and how humans behave in a social and cultural context. There have been several attempts to bridge the gap between the different approaches, but still there are “fundamentalists” on each end of the spectrum who continue to disclaim the importance of their counterparts (Adler, 2009; Engel, 1977; Goldberg, 1992).

The problem with the term mental disorders is that it covers such a large number of various conditions and states, which are explained to different degrees by social, psychological, or biological factors. In his critical work on the use of ‘social constructions’, Hacking (1999) has cited various mental disorders to exemplify how the natural and social sciences differ in the act of classifying objects. Classifications in the natural sciences are primarily inert and independent of their objects, which Hacking calls ‘indifferent kinds’. The classification of an object in physics, for example, does not change that object. Hacking give the example of Quarks (see pp 68-72). The quark as object and the quark as classificatory term do not interact.

By contrast, classifications in the social sciences interact with their objects in a two-way process. The human objects of classification understand the classification and can come to change or modify their behaviour according to their understanding of it. These changes in the human take place in accordance with how the classification is understood. This is what Hacking calls the ‘looping effect’. The object of study in social sciences Hacking calls ‘interactive kinds’. When it comes to mental illnesses Hacking means that they are simultaneously indifferent and interactive. Several diagnoses have been shown to have biochemical, neurological, or genetic causes. At the same time expressions, treatment, and outcomes are strongly determined by a complex context in an ever changing society. As we understand Hacking’s theoretical model, there are more or less indifferent and interactive elements in mental disorders, and these disorders are all moving back and forth along a continuum running from indifferent to interactive. Hacking (2002) has chosen to categorize what he views as a different type of disorders as ‘transient’. A transient mental illness is

An illness that appears at a time, in a place, and later fades away. It may spread from place to place and reappear from time to time. It may be selective for social class or gender, preferring poor women or rich men. I do not mean that it comes and goes in this or that patient, but that this type of madness exists only at certain times and places. (p. 1)

Examples of transient illnesses are mad travel disorder, the diagnosis that the book *Mad Traveler* is based upon, as well as hysteria and anorexia.

The focus in this dissertation lies on the social and cultural aspects of mental distress, and some criticism will be levelled against posing the biomedical model as almighty. Different explanatory models are equally important in the attempt to create a holistic understanding of mental disorders that include their prevention and treatment.

Since the aim of this study was in part to investigate how people themselves perceived mental ill health, we have not tried to offer a definition of the term. In most of our interviews the term mental ill health (*psykisk ohälsa* in Swedish) was used, which was chosen since we felt it was the broadest term possible. In our texts we have used mental ill health, mental illness, and mental disorder with the last to great extent being viewed as a pathological process, while mental illness was seen as the subjective experience of it.

## Cultural psychiatry

The research concerning the utilisation of mental health services among immigrants could be described as belonging to the field of cultural psychiatry. Even though psychiatry is organized as a medical specialty, it embraces a complex set of research disciplines, professional groups, and political forces. Psychiatry is recognized as having different dimensions. In the 1970s Engel (1977) presented the bio-psycho-socio model (BPS), but there still seems to be an emphasis on the biological dimension. Steven Sharfstein, The president of the APA (American Psychiatric Association) in 2005-2006, wrote that “we have allowed the biopsychosocial model to become the bio-bio-bio model” (2005, p. 3). But voices from within psychiatry seems to be divided. While some say that the BPS model is still very relevant (Adler, 2009), others argue for a reconceptualization of psychiatric illness from disorders of the mind to disorders of the brain (Insel & Wang, 2010).

Cultural psychiatry can briefly be described as an area concerned with understanding the impact of social and cultural differences on mental disorders and their treatment (Helman 2001). It is a field directed both towards research and the delivery of service (Kirmayer & Minas, 2000). The term *cultural psychiatry* has been thoroughly discussed, and equally widespread are the expressions *transcultural psychiatry* and *cross-cultural psychiatry*. In this study the term chosen will be cultural psychiatry. The area may be divided into three branches. The first is cross-cultural comparative studies, focusing on the prevalence of psychiatric disorders. The second is the study of cultural variations in the expression of illness among migrant populations and the related efforts to respond to mental health needs. The third is the cultural critique of psychiatric theory and practice (Kirmayer & Minas, 2000).

Irrespective of how universal broad categories of mental illness may be, decades of cross-cultural research have demonstrated that definition of normality, psychological experiences, expression of symptoms, patterns of onset, duration, and even clustering of symptoms into categories vary across cultures and time (Kirmayer & Minas, 2000). Regardless of whether culturally unique mental disorders exist, or if there are simply differences in views of illness and behaviours associated with universal psychiatric diseases, new situations occur with the movement of people between countries and cultures. For example, clinicians encounter difficulties in treating patients of different backgrounds and, therefore, presuppositions and bias lead to misdiagnoses. An example of this is a study conducted by Loring & Powell (1988), who tried to answer

the question: Using the DSM-III, do psychiatrists provide different evaluations of clients based on sex and race? They sent two case narratives written in the style of DSM-III, with criteria supporting a diagnosis of schizophrenic disorder and dependent personality disorder, to psychiatrists in the US. Since the study intended to investigate how the gender and race of a client may influence the choice of diagnosis, different case narratives were provided with gender and race attributes. All psychiatrists received the same two cases, but approximately one-fifth of the clinicians received case describing a white male, a white female, a black male, a black female, or a case in which the clients race and sex was not disclosed. Most correct diagnoses resulted when no identifying characteristics were provided. Black males were given more severe diagnoses than any other group.

### *Classifying mental disorders*

In recent decades, epidemiological research in conjunction of psychiatry has gone from a marginalized field to becoming a large, developed discipline generating standardised clinical assessment instruments and a widespread classification system for mental disorder: Diagnostic and Statistical Manual of mental disorders (American Psychiatric Association, 2000; Good, 1997; Kleinman, 1991). This manual, referenced by psychiatrists all over the world, was developed by the American Psychiatric Association and sets out operationalised inclusion and exclusion criteria for each psychiatric diagnoses listed. DSM was originally written only for use in the North American context and was first published in 1952. Since then it has appeared in 20 different languages in numerous countries. The first edition of DSM carried 104 psychiatric categories, and the fourth edition in 1994 had 357. The first two versions of DSM reflected the prevalent psychodynamic psychiatry (Mayes & Horwitz, 2005), although biological perspectives from the Kraplins classification system also had been incorporated (Wilson, 1993). Symptoms were not specified for every disorder and the diagnoses were explained by underlying conflicts or faulty adaptation to life problems. In the third and fourth editions, DSM was mainly concerned with signs and symptoms of mental disorders, rather than dealing with underlying causes. Critics of the DSM have questioned its concentration on neurophysiological findings, thus understating the importance of social, cultural, and psychological aspects (Kleinman, 1991; Widiger & Sankis, 2000). In preparing DSM-IV, a task force of cultural psychiatrists and anthropologists were assigned the mission of adding cultural aspects. A cultural section was formulated for the introduction so that psychiatrists would be able to take

culture into account in the clinical application of DSM to patients. To the great disappointment of the taskforce that text was never included in the introduction, but appears in the ninth appendix. Furthermore the task force agreed upon a Glossary of Culture-Bound Syndromes on the condition that also “Western” syndromes such as anorexia nervosa and agoraphobia would be included. The glossary appeared, but without the syndromes culture-bound to the West and in a place in the DSM where it merely bears a sense of exoticism (Kleinman, 1997; Martinez-Hernández, 2000).

Another classification system is The International Statistical Classification of Diseases and Related Health Problems (ICD) (WHO, 2009), which provides codes for classifying diseases in general. ICD is published by the World Health Organization and used worldwide for morbidity and mortality statistics, social security systems, and as a support in clinical practice. This system is designed to promote international comparability in the collection, processing, classification, and presentation of statistics. The ICD also includes a section that classifies mental and behavioral disorders (Chapter V). It has developed alongside DSM, but there are still significant differences, which an International Advisory Group has been assigned to bridge<sup>1</sup>. In an international survey it was found that ICD was more frequently used in clinical practice, while DSM saw more application in research (Mezzich, 2002).

### Culture for good and for bad

One of the aims of this research project has been to focus on contexts where culture might have a crucial influence on different perceptions and ways of understandings. The word culture has been described as one of the two or three most complicated words in the English language (Williams 1981). At the beginning of the 1950s Kluckhohn and Kroeber (1952) presented 161 different definitions of the term. The discipline in which it has generated the most heated debate is anthropology. The discourse on culture infected anthropology from time to time that people were advised not to use the term. The concept, however, cannot be avoided. In order to illustrate its complexity of it and prevent possible misunderstandings, some brief comments may be in order.

At the end of the nineteenth century Edward Burnette Tylor, offered a definition of culture that is still widely cited: “Culture, or civilization, taken in its broad, ethnographic sense, is that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man

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<sup>1</sup> For more information see [http://www.who.int/mental\\_health/evidence/en/](http://www.who.int/mental_health/evidence/en/)

as a member of society.” (Keesing & Strathern, 1998 p. 15) Several attempts have been made to narrow down this definition. One commonly used today, developed by Geertz (1993), is that culture represents those abilities, conceptions, and behaviours that people acquire as members of a society. The concept of culture is often misunderstood and misused; the most common problem is that it is essentialised by reducing it to a set of fixed properties or characteristics. In an encounter between two people with different backgrounds there is a mutual risk that they treat each other based on preconceptions of how someone from that specific culture ‘is’.

Similarly, there is the danger of making broad generalizations about members of any society without taking into account that differences among people in the same group may be as marked as those between members from different societies. It is possible to talk about a typical behaviour, pattern, or situation characteristic of a group of people, but one has to be aware that it is not necessarily true of every individual. Culture can never be taken out of its particular context. With regard to immigrants in the West, it has been demonstrated that professionals easily lose sight of the fact that identity processes vary considerably in the dynamic interaction between immigrants and host societies (Eastmond, 1998). Consequently, there is no way to know a priori what role “culture” plays for a certain individual.

Finally, too large a role may be attributed to culture in situations where such aspects have no de facto bearing and where other elements may be of greater significance. Kleinman (2006) illustrates this in the case of a Mexican family in the United States. The mother had died of AIDS, leaving a four-year-old son who was HIV-positive. The boy, who had to see a doctor regularly, did not come as frequently as recommended. A social anthropologist was consulted in order to determine what *cultural* factors caused his father to miss the scheduled appointments. The consultant found that there were no cultural issues at all. The father was working two jobs to support his family and simply did not have time to bring his son.

Kirmayer & Minas (2000) have described different ways in which the notion of culture is used in psychiatry. Most often it is perceived as a problem of communication between clinician and patient. Culture is something that patients carry in the form of odd values and beliefs, along with strange language and nonverbal communication.

Instead of only criticising the use of ‘culture’, Kirmayer & Minas (2000) suggest ways culture can be used in psychiatry:

The most helpful use of the notion of culture recognizes that psychiatry is the product of a cultural world, which leads to a critical appreciation of the implicit assumptions and historical grounding of our theory and practice. This awareness of our own assumptions opens the door to real dialogue with patients and colleagues from diverse backgrounds. (p. 440)

### **Doing research with interpreters**

To carry out research in multicultural settings often means that researchers have to work with interpreters, as in this research project. Working with interpreters in qualitative research has methodological implications. In recent years the demand for information concerning ethnic minorities has grown and the use of interpreters has consequently increased (Kapborg & Berterö, 2002; Temple & Edwards, 2002). The lack of attention given to interpreters in cross-cultural research has been cited by authors from different disciplines (Edwards, 1998; Kapborg & Berterö, 2002; Temple & Edwards, 2002; Wallin & Ahlstrom, 2006), but of late years the number of methodological articles concerning interpreters has increased and today the discussion includes areas such as nursing science, social work, and psychology.

Most researchers working with interpreters are aware that communication problems and the use of interpreters in one way or the other influence the outcome of the interview (Kapborg & Berterö, 2002; Marshall & While, 1994; Wallin & Ahlstrom, 2006), although this issue is seldom examined. The number of articles on the use of interpreters in research is growing, yet most authors continue to focus on procedures for a successful interview, and the need to adhere to rigorous techniques.

The main focus before carrying out the interview is often choosing an interpreter, for which recommendations vary (Squires, 2008). Some argue that an interpreter should be a well-established person from the group in question, that is, someone the informant has confidence in, feels safe and secure with, and is comfortable enough to sensitive topics (Hennings, Williams, & Haque, 1996). Others hold that an interpreter who is known may inhibit interviewees and hinder them from talking about sensitive topics (Murray & Wynne, 2001).

Authors have recommended matching interpreters and participants in respect to sex, age, religion, ethnicity, or other characteristics that could effect the dynamics of the interview situation (Freed, 1988).

Finally, researchers continue to discuss how an interpreter should work. Their role is described as either passive or active. The former refers to an interpreter translating verbatim, while the latter considers translation of more than what is said explicitly, and highlights cultural variations and the need to provide the researcher with further explanations (Wallin & Ahlstrom, 2006).

### **Children of parents with mental illness**

In the interviews for the first study (Paper I) several informants brought up the issue of children. Some of them expressed frustration that youths were spending time fighting with peers, robbing people on the street, and vandalising buildings in the area, which they explained by lack of attention from the parents. It was suggested that parents who were depressed might not have the strength to bring up their children properly. Some commented on the difficulty of living in a new society with a different view of raising children.

Informants also said that children were worried about the illness of their parents. For example, a man from Iraq in treatment at the Red Cross explained that his wife, who yet had not been treated, caused a lot of worries for their children.

It has been well-established that parental mental illness significantly affects the life situation of dependent children, both directly and indirectly (Kessler et al., 2010; Mordoch & Hall, 2002; Östman, 2008a).

### **Prevalence**

Many children live with a parent suffering from mental illness. Studies from the US and the UK estimate that from 20% to 50% of all adults receiving psychiatric care have dependent children (Fudge, Falkov, Kowalenko, & Robinson, 2004). In the US nearly half of the general population report a lifetime prevalence of mental disorder. More than half of those males and two-thirds of those females are parents (Nicholson, Biebel, Hinden, Henry, & Stier, 2001). In a Swedish study of 137 individuals in inpatient and outpatient services, 36% were parents of minor children (Ostman & Eidevall, 2005). The proportion of psychiatric patients admitted to hospital who have minor children is fairly constant over time – approximately one-third, according to a study that also indicated that a decreasing proportion of such patients retain the custody of their children (Ostman & Hansson, 2002).

### **Impact**

The negative impact on children from living with a mentally ill parent has attracted considerable research and policy attention in recent decades (Cowling,

2004; Goodman & Gotlib, 1999; Royal College of Psychiatrists, 2002). The association between parental mental illness and a wide range of adverse outcomes for their children is known. Moreover, parental mental illness, due to both genetically and environmental factors, increases the risk for children of mental ill health (Cowling, Luk, Mileskin, & Birlson, 2004; Lieb, Isensee, Hofler, Pfister, & Wittchen, 2002; Scourfield & McGuffin, 1999; Srinivasa Raju, Russell, John, Jeyaseelan, & Cherian, 2001). There is also the additional issue of parents being unable to maintain a satisfying parenthood and sound relations with their children because of their illness (Thomas & Kalucy, 2003). The risk of a less favourable economic situation and potential problems with social and marital relations may have an indirect affect on the children (Goodman & Gotlib, 1999; Tebes, Kaufman, Adnopo, & Racusin, 2001). Furthermore these children have poorer prospects than others of the same age with regard to school attendance (Farahati, Marcotte, & Wilcox-Gök, 2003). A central theme in several studies deals with the exposure children may experience related to the shame and stigma that mental illness is often associated with (Diaz-Caneja & Johnson, 2004; Hinshaw, 2005; Ostman & Kjellin, 2002; Tanner, 2000). In some families children have problems with the mentally ill parent becoming unpredictable or violent towards the child. A British study on child mortality has shown that a small but significant group of children die every year because of mentally ill parents (Fudge et al., 2004).

Since the middle of 1990s there has been increased focus on how children of parents with mental illness experience their life situation (Garley, Gallop, Johnston, & Pipitone, 1997; Mordoch, 2010). Some studies attempt to reflect a picture from within, allowing children to describe their conditions living with a mentally ill parent (Hindle, 1998). There are also descriptions of how adults experienced growing up with parental mental illness (Cowling, 2004; Dunn, 1993). Such stories depict a vulnerable and dolorous life situation where interventions from society did not seem to satisfy these children's needs. Among other things it can be difficult to understand the illness and to learn how to recognise and handle the symptoms (Handley, Farrell, Josephs, Hanke, & Hazelton, 2001). Children living with a mentally ill parent can experience a vast shift of roles, where the child get to function as the parent of his or her own parent (Stengler-Wenzke, Trosbach, Dietrich, & Angermeyer, 2004).

Despite a large amount of research concerning parental mental illness in general, the experience of immigrant children in particular is an under-researched area.

## Interdisciplinarity

Being situated in a multidisciplinary context<sup>2</sup> can easily contribute to confusion. Some colleagues find one's methodological procedure presented too detailed while others find it obscure or not rigorous enough. About fifteen years ago Bourdieu (1991) maintained that scholars should abandon the dispute between quantitative and qualitative methodology, but it has proven not to be easy. One is constantly reminded of the varying traditions that are based on different assumptions of study objects, reality, and truth.

There are several definitions of interdisciplinarity. In *Improvising Theory*, Cerwonka and Malkki (2007) discuss matters concerning interdisciplinarity, but the concept is not fully elaborated in terms of a definition. Their example of interdisciplinary research is a political scientist using anthropological methods, or as Malkki describes it “an alien repertory of research techniques” (p. 165). A different definition is presented by Rowe (2008):

By “interdisciplinary research,” we refer to a true collaboration—a melding of disciplines—not just the addition of techniques and technology from one field to research in another. In addition, we generally refer to collaborations across major disciplinary boundaries (such as combinations of physiology and social sciences) as opposed to the more common, and also powerful, combinations within broad disciplinary boundaries (such as addition of anatomical studies—i.e., electron microscopy—to efforts in basic cellular biology). (p. 4)

According to this definition the political scientist mentioned above is not practicing interdisciplinary research, by just adding the techniques of fieldwork from one field to another. In the area of cultural psychiatry there are several examples of eminent scholars including Arthur Kleinman, Laurence Kirmayer, and Ellen Corrin, who are educated in both medicine and anthropology. Their work could most likely be called interdisciplinary. No matter if there has been a melding of disciplines in this research project or not. Having wrestled with several of the issues related to different approaches, we have come to focus on the challenges and opportunities of interdisciplinarity, which could be encountered on different levels, here exemplified in the area of cultural psychiatry.

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<sup>2</sup> By multidisciplinary context we mean being a researcher with an anthropological background investigating an issue predominantly situated in the field of medicine in a faculty where colleagues from various disciplines such as nursing and social work comment on one's work.

## Challenges and opportunities

The whole area of cultural psychiatry may be called interdisciplinary, trying to combine different perspectives on mental health and illness. Cultural psychiatry tries to understand the impact of social and cultural differences on mental disorders and their treatment (Helman, 2007). The two main theoretical approaches included in the domain of cultural psychiatry, those of medicine and anthropology, differ considerably. Research in medical science is predominantly associated with positivism and empirical knowledge, and is based on quantitative data. Anthropology, by contrast, largely deals with qualitative methods related to hermeneutics, interpretation, and reflexivity. Thus, the two disciplines approach the field of cultural psychiatry with different paradigms<sup>3</sup>.

The difficulty with interdisciplinary research is to arrive at a compromise with one's own disciplinary traditions in order to create something new. As stated by Cerwonka (2007), interdisciplinary research is not an easy task:

The borders of disciplines are historically constituted and, while there is a logic to the academy's categorization system, disciplinary borders are nonetheless fundamentally arbitrary. Interdisciplinary work, in addition to devising new epistemologies and research forms, is renegotiating a historical and politically charged categorical system that orders regimes of knowledge, status, and authority. (p. 9)

The first challenge concerns one's epistemological background and perceptions of the world. Psychiatry is, both from a theoretical and a clinical point of view, mainly based on Western assumptions and theories of science. Medicine is generally associated with realism and the belief that truth can be reached through appropriate scientific methods. In traditional medical research, humans are primarily viewed as biological beings, and emotions, experiences, and culture are not usually regarded as important factors for the outbreak, course, and recovery from a disease (Wallén, 1996). Jensen (1985) has described the theoretical approach in medicine by using the term medical essentialism, which he refers to as the dominant view for more or less the whole tradition of medicine. According to this position diseases are treated as if they have a defined, inherent core, an essence, which a skilled doctor is able to find. The task of a physician is to diagnose and prescribe the right treatment, and the same is true for psychiatrists. Mental disorders, in Hacking's words, are presented as if they were *indifferent kinds* (Hacking, 1999).

<sup>3</sup> This is admittedly a highly simplified picture since there are features of quantitative research in anthropology, as well as qualitative studies carried out in medicine.

The critique of the theoretical approach in medicine comes from other disciplines such as social science, but also from researchers representing the own discipline. The social sciences in general, and anthropology in particular accuse psychiatry of not taking social and cultural factors into consideration. The fundamental dogma of anthropology is dominated by postmodernist thoughts defending relativism, interpretation and reflexivity.

In *Rethinking Psychiatry*, Kleinman (1991) has illustrated the gap that exists between psychiatrists and anthropologists in their view of mental disorders. The concept of culture is treated in most psychiatric textbooks as unessential to mental health or psychiatric treatment, while in anthropology the term culture is one of the most commonly used and debated. On the other hand, Kleinman continues, “The extreme relativism of some psychiatry anthropologists is as outrageously ideological as is the universalistic fundamentalism of some card-carrying biological psychiatrists.” (p. 33)

The second challenge is not only that epistemological and methodological traditions differ, but different disciplines generally have different objectives. Medicine and social work are primarily practical disciplines, whereas anthropology deals to a considerably greater degree with theoretical issues and formulating a conception of the world.

At an international conference on transcultural psychiatry held in 2010 in Amsterdam, one of the most prominent researchers in the area, Laurence Kirmayer, related an anecdote about the collaboration between an anthropologist and a clinician. The anthropologist gives a thick description of an enormously complex situation around a case and the psychiatrist responds, “wow, but what do we do?”. At this time, Kirmayer concluded, the real interdisciplinary work begins, and one needs to look at the opportunities of combining different approaches.

Reality consists of various ontological levels, such as biological, social and, mental, which is why we have different academic disciplines. Phenomena may require a variety of levels and disciplines to be understood as completely as possible. Mental illness is definitely belonging to this category. In interdisciplinary research different perspectives are perceived as complimentary instead of competing.

## **Key theoretical concepts**

### **Resilience**

The concept of resilience was first used by child psychiatrist Michel Rutter in his frequently cited article *Resilience in the Face of Adversity*, published in 1985. Interest in studying children who had had a positive course of development

despite being exposed to severe risk had appeared already in the 1970s, under the category “invulnerable children” (Masten, Best, & Garmezy, 1990; Rutter, 2000). Resilience has been defined as successful adaptation in response to adversity (Zautra, Hall, & Murray, 2010), but, there is no consensus regarding the meaning and new definitions regularly appear. For example, Ungar (2008) has focused on a cultural dimension of resilience and has made an effort to unify different definitions of both outcome and process in order to remove some the value-laden aspects that are accommodated in the term:

“In the context of exposure to significant adversity, whether psychological, environmental, or both, resilience is both the capacity of individuals to navigate their way to health-sustaining resources, including opportunities to experience feelings of well-being, and a condition of the individual’s family, community and culture to provide these health resources and experiences in cultural meaningful ways.” (p. 225)

A number of researchers have tried to address conceptual, theoretical, and methodological obstacles surrounding the concept of resilience. Masten and colleagues (1990) have distinguished three kinds of phenomena being referred to as resilience: (1) at-risk individuals showing good outcomes (2) people who maintain good adaptation under threat, and (3) recovery from trauma. In this work resilience refers to the first of these three meanings.

Resilience is described as value-laden in the sense that there is an arbitrary judgment involved in defining of risk factors and adversity. The same can be said of good outcome and successful adaptation (Liebenberg & Ungar, 2009; Masten, 2001). For example, risk may be assessed statistically, subjectively, or objectively, and these diverse approaches to risk do not always coincide. The same type of risk factors can affect people differently and depends both on the individual and on contextual circumstances (Luthar, Sawyer, & Brown, 2006; Ungar, Clark, Kwong, Makhnach, & Cameron, 2006). Furthermore, the evaluation of successful adaptation is associated with normative judgments (Kaplan, 1999). What may be considered an undesirable outcome in one context may be defined as resilience in another. Ungar (2010) refers to this phenomenon as *hidden resilience* and gives the following description: “At the intersection of individual definition of success and the appraisal of what resources an environment realistically has to offer lies hidden resilience” (p. 417).

### *Related concepts*

During the thirty years of resilience research several concepts signifying overcoming or resisting distressing life events have emerged.

The Salutogenesis Model was formulated by the medical sociologist Aaron Antonovsky at the end of the 1970s. This theory of health and illness focuses on how certain personal dispositions serve to make individuals more resilient to the stressors they encounter in daily life. Antonovsky (1987) found that people remained healthy if they had a 'sense of coherence', which is created through various internal and external factors.

Similar thoughts, within the discipline of social work are incorporated in the Strength Perspective. It holds that every person, family, and community has capacities that can be drawn upon to overcome problems. Trauma, illness, and struggle are seen by the Strength Perspective as opportunities for challenge and growth. Consequently, the focus of this approach is on the capacities and strengths of clients, rather than on their problems, which are usually left to be dealt with by social workers (Saleebey, 2006).

The concept of Coping was introduced in the 1980s by psychologists and refers to "an individual's effort to master demands (condition of harm, threat, or challenge) that are appraised (or perceived) as exceeding or taxing his or her resources" (Monat & Lazarus, 1991, p. 5). The coping process consists of two major modes: problem-focused and emotional-focused. Problem-focused coping is about changing things experienced as problems in the environment, that is, tackling stress-factors. Emotional-focused coping do not involve strategies that alter the damaging or threatening conditions but seek to make the person feel better by relieving the emotional impact of stress.

All of the perspectives above, including resilience, involve focusing on strength and virtue, rather than weakness and suffering. The concepts mainly differ by in which field they emerged from and consequently where they are used. Coping and the Strength Perspective also differ from the other concepts in that they are not talking about risks. One does not need to be at risk to be able to cope with a situation. According to the Strength Perspective the term 'at risk' has become a stigmatizing code and "a true strength-based framework avoids this re-packing of old deficit-based concepts" (Saleebey, 2006:99).

### **The looping effect**

We have referred earlier to the controversy between two different approaches to the study of mental disorders: realism and constructivism. Generally, realism offers a bio-medical explanation, whereas social science suggests that psychiatric

diagnoses are also socially constructed and contextually dependant. Hacking argues that the two attitudes are not only compatible, but also mutually supporting (Hacking, 1995; Hacking, 1999). This collaboration results in what Hacking calls a looping effect. He gives examples of autism and homosexuality, describing how classifications and images give structure to perceptions and are ratified.

It was once argued that that calling a person a juvenile delinquent (etc.), and institutionally confirming that label, made the person adopt certain stereotypical patterns of behaviour. When a youth was labelled as J, he assumed more and more of the characteristic features of J. That is a claim about labelling *individuals*. I am sure that there is some truth in it for some individuals. I go two steps further. I assert that there are changes in individuals of that kind, which means that the kind itself becomes different. Next, because the kind changes, there is new knowledge to be had about the kind. But that new knowledge in turn becomes part of what is to be known about members of the kind, who change again. This is what I call the looping effect for human kinds. (1995, p. 369)

In short, the looping effect means that *how* we classify can affect those who are being classified. In addition, these changes in the classified human can then change how the classification is understood, hence the 'loop'.

# AIMS

The general objective of this dissertation was to study the putative underutilisation of mental health services in a multicultural context.

The specific aims of each paper were:

To illustrate how underutilisation of mental health services among immigrants could be explained by a different perception of mental ill health. (Paper I)

To identify significant issues that arise when using an interpreter as a partner in research. (Paper II)

To investigate aspects of the life situation of immigrant children living in a family with at least one parent suffering from mental illness. (Paper III)

To explore whether central ideas in resilience research may contribute to understanding the utilisation of mental health services among immigrants in the West. (Paper IV)

# METHOD

When presenting a method, the epistemological and ontological base is either mentioned implicitly or explicitly. Inspired by Bourdieu and colleagues (1991), comments on those issues interspersed throughout method section.

The overall design of the present study is indebted to Lincoln & Guba's *Naturalistic Inquiry* (1985). The key element of such research is that "studies are virtually impossible to design in any definite way before the study is actually undertaken" (p. 187). Instead of a fixed design the procedure is described in terms of a flow or development. Only the topic for Paper I had been decided when this research project was started; thereafter it has all been a process. Naturalistic inquiry was chosen because it embodies assumptions and values of the researchers' way of perceiving the world, and it allows informants to express personal views and experiences in a broad sense that is suitable for this kind of explorative research studies. This section will begin with a short description of the research site. The methodological process will then be described for each paper.

## **Research site: a multicultural context**

Much of the empirical data for this project was gathered in the borough of Rosengård. In one way the specific area is of less importance: voices of immigrants capturing aspects of mental ill health could be similar regardless of what part of the city they live. In fact, people in Rosengård move frequently. Over a period of four years, nearly half of the population in the borough changed their residence (Malmö Stad). In another way, the particular neighbourhood has characterized the research process a great deal, as will be elaborated below.

Rosengård was built in the 1960s and 1970s as a part of the so-called Million Programme, run by the government. Its aim was to create one million dwellings

in a ten-year period to guarantee everyone a home for a reasonable amount of money. Almost 23,000 people inhabit Rosengård today, and a majority (86%) has foreign background. The largest groups of immigrants are Arab Muslims, predominantly from Iraq and Lebanon, and people from the former Yugoslavia (Malmö Stad, 2008). It is a neighbourhood with a tarnished reputation. With high unemployment rates, large social problems, and recurrent riots and actions of violence, Rosengård has become a target for journalists, researchers, and social workers trying to change its undesirable pattern (Hallin, Jashari, Listerborn, & Popoola, 2010; Ristilammi, 1994). This aspect has affected the research process in several ways. From the start we met people who asked “Why Rosengård? Why always Rosengård?” Residents, and to an even greater extent, people who had worked in the borough for many years described Rosengård as a laboratory in which the residents were guinea pigs. Thus, in some contexts there was general resistance to participate in projects. Furthermore, the bad reputation of the area continued to be a common topic of conversation in several meetings both with people living and working there. Because of the large discrepancy that often exists between how residents experience their neighbourhood and how it is presented in the media, informants were eager to tell their side of the story, sometimes quite defensively.

In the title of this dissertation we have chosen to use the term multicultural context. The reason for not using the term immigrants is that the investigation concerns not only the individuals, but also the surrounding environment and the discourse of the research area. Immigrants are not a homogenous group. People migrate for different reasons, they come from many different places and have various socio-economic backgrounds. Some are migrant workers in search of employment and others migrate to reunite with their families. There are political exiles or refugees who have been forced to leave their country for another. Also, many refugees are fleeing ongoing wars. Finally, there are students who initially move to study and then choose to stay. This dissertation must be understood in the context of the heterogeneity of migration and immigrants. Immigrants are here defined as those born abroad or those born in Sweden but who have two parents born abroad. There are difficulties in referring to other studies since different terms and definitions are used. Sometimes the term refugee is applied to all immigrants, and in other studies, groups are strictly divided according to purpose of migration or country of origin.

## Data collection

In addition to interviews, the studies in this dissertation involve different kinds of sources: informal meetings and conversations, field notes, journalistic and scientific articles, television programmes, and websites. The various sources have helped to broaden the perspectives of the researchers, both regarding the topic and context, and concerning method and reflexivity.

### Paper I

The first study is based on some thirty interviews with people between ages 18 and 65 with connections to Rosengård. Either they were living in the borough or they were professionally engaged in matters concerning people in the area. Informants were randomly chosen using the snowball method, which "yields a study sample through referrals made among people who share or know of others who possess some characteristics that are of research interest" (Biernacki & Waldorf, 1981, p. 141). The initial contacts were made with people working for different organizations, associations, schools, and health care centres, and with public officials in the area. Caution was exercised when asking informants to name other potential interviewees, in part since issues regarding mental ill health often were perceived as sensitive by the informants, and also because various social positions and power relations could disturb the idea of voluntary participation.

The participants came from a number of ethnic backgrounds. Their countries of origins included Iraq, Iran, Lebanon, Palestine, Afghanistan, Bosnia, Kosovo, Algeria, Poland, Somalia, and Sweden. All interviewees of Swedish background were professionals working in the area. However, several informants employed in the borough also were of immigrant background.

The sampling mode of choice in naturalistic research is generally maximum variation sampling (Lincoln & Guba, 1985). This entails the researcher trying to find many different views and specifics to show variations in findings, rather than general conclusions. In this study our informants had various ethnic backgrounds. They were also differing in gender, even though there were slightly more males among the residents and more females among those informants who worked in the area. Many informants were Muslims, since most immigrants in Rosengård come from the Middle East and the Balkan. In a naturalistic inquiry, informants are best chosen after the previous interviewee has been interviewed. Sometimes several people from fairly homogenous groups desired to participate in the study. Their offer was declined by the researcher in order to insure maximum variation. The aim was to investigate the perception of mental ill health in general, and not

focus specifically on people who suffered from mental illness. In some interviews the fact that the person was not an attribute from a mental illness thus came out, but it was not something we actively sought for in an interviewee.

The locations of the interviews were always chosen by the informants themselves. As a result, interviews took place in people's homes, at their jobs, in schools, and at the library. The interviews were conducted and transcribed in Swedish and interpreters were engaged in nine of the interviews. Because the participants had various backgrounds and mother tongues, it was not possible to use the same interpreter for all the interviews. Issues concerning the use of interpreters in research will be further elaborated later in the section.

## Paper II

The background of the second paper was an interview for Paper I with a Pashto-speaking informant conducted together with interpreter. The whole interview situation struck the researcher as strange. The atmosphere was tense and the answers conveyed by the interpreter did not seem to correspond with the questions posed. In order to better understand this particular interview, we decided to get a second opinion of the interpretation by having the interview translated one more time. In order not to confuse the new translator, the audio file was edited and the spoken words of the researcher and the translation of the first interpreter, i.e., all that was said in Swedish, were removed. What remained was the conversation in Pashto between the interpreter and the informant. In order to have a standard of comparison, a second interview from our study was chosen, this one conducted together with an Arabic interpreter. This interview was selected because it was experienced by the researcher as rich and fruitful, in contrast to the Pashto one.

The edited audio files were sent to independent translators, who were living and working in another part of Sweden. They were translated and transcribed into Swedish. By reviewing and comparing the different transcriptions, pitfalls and opportunities that could appear in working with interpreters were highlighted.

## Paper III

This study was based on semi-structured interviews with eleven children. The inclusion criteria were children between ages 10 and 18 of immigrant background, currently living with a mentally ill parent. Due to different recruitment problems (see below), eight out of the eleven children participating in the study lived in parts of Malmö other than Rosengård. The children interviewed came from various ethnic backgrounds. Their countries of origin included Iraq, Lebanon, Palestine, Chile, Bosnia, Kosovo, and Iran. Nine of the children had parents suffering from

affective disorders (including depression, bipolar, panic and anxiety disorders) and one parent was diagnosed with schizophrenia. Most of the children were recruited through a psychiatrist working with adults, a social worker, and staff at the division of child psychiatry. Those professionals provided us with information about the parents' diagnoses, with the consent of the parents.

Data were gathered using open-ended questions in semi-structured interviews of up to 1.5 hours in duration. Each child was interviewed individually, except for one occasion on which two sisters participated together. Five of the children were interviewed by a team of two researchers. The remaining six interviews were conducted by a single researcher. All interviews were carried out in Swedish, two with linguistic support from a cultural mediator. Most of the interviews took place in the informant's home, but some were done at the child's school, depending on their preference. In two instances the child requested that the parents be present.

### *Recruiting the children*

When we began contacting people to arrange meetings and as we prepared informational brochures, we realised it was going to be difficult recruiting children. However, we had received written consent for our study, both from the City Manager of Rosengård and the director of the psychiatry division, covering the whole city of Malmö. We tried to reach the children through places where they themselves were involved, such as schools, child psychiatric services, social services juvenile division, and childrens' organisations, and through their parents via psychiatry, healthcare centres, psychologists, and other organisations. Ten months later we had made contact with over fifty people who knew of children or parents who might be appropriate interviewees for our study but we had only met with four children for interview. We then decided to expand our inclusion criterion, which had been limited to children in Rosengård, to also include children in other parts of Malmö. Finally, we managed to get in contact with two professionals who were not afraid to ask their patients and clients if they would participate, which quickly led to seven more interviews. The main reason why some professionals were not able to help us was because, as they told us, they did not dare to ask parents about such a sensitive topic as mental illness.

### Paper IV

The fourth study grew out of ideas that emerged from the work with Papers I & III. The large body of literature concerning utilisation of mental health services among immigrants in the West, as well as literature on children living with

parental mental illness, seemed strongly focused on vulnerability, in contrast to the expressions of resilience that were shown in our studies. To our knowledge the concept of resilience had not been applied to utilisation research, prompting us to investigate whether the use of this concept could add anything to the field of utilisation research.

We structured our approach in three stages: First we described research on the utilisation of mental health care among immigrants. Second, the theoretical ideas of resilience were outlined. Third, we discussed how the concept of resilience could contribute to the research of mental health care utilisation among immigrants.

### **Processing the data**

#### Papers I & III

All interviews were tape recorded and transcribed by the researcher who had conducted them. Data analysis occurred simultaneously with data collection process, enabling a consistent reflection of the material. The process of analysis required sifting through the transcriptions over and over again, looking for patterns and constructing categories. To suggest that categories simply emerge in the process of analysis is what Lincoln & Guba (1985) call “an enormous understatement of the effort, ingenuity, and creativity that are involved” (p. 340). The constant comparative method is applied in naturalistic inquiry. It is similar to the method used by Glaser and Strauss but with the major difference that in naturalistic inquiry it is a means of processing data, whereas in Glaser and Strauss’ model it is a means of deriving theory. In the constant comparative method, units found in the transcriptions are constantly compared with other units and with broader categories. In this way the different patterns are subjected to continuous questioning throughout the research process and as a result deviant cases become visible. Constructing the data includes both deriving the descriptive categories and explaining them (Lincoln & Guba, 1985). To strengthen the trustworthiness of the findings the categories and the conclusions continued to be discussed throughout the process among the authors as well as in other settings with academics and professionals. For Paper I the redundancy criterion appeared to be reached as no new information changing the categories emerged. Due to recruitment problems, the criterion of redundancy could not be reached for Paper III.

## **Ethical considerations**

Studies I and III were approved by the Regional Ethical Board in Lund (Dnr 101/2006 & 215/2007). An additional ethical approval was requested and received for Study II (Dnr 13-2008). Collected data was treated in such a way as to protect the integrity and identity of the participants. Thus, all names mentioned in different papers have been changed. Informed consent was given by all participants and, in the case of Paper III, by the children's parents as well. Both the informational letter and the paper of informed consent were offered in a range of languages. Interviewees were informed, both in writing and orally that participation was voluntary and could be interrupted at any time without explanation. In cases where informants indicated that they were in need of care, we suggested where they could turn.

# SUFFERING AND RESILIENCE: RESULT AND DISCUSSION

## **Underutilisation of mental health services**

The aim of the first study was to explore reasons why inhabitants of Rosengård underutilise mental health services. Possible explanations were found in a variety of structures on different levels. First, one must consider how expressions of mental distress are perceived. Second, psychiatric care is not viewed as the only treatment option. Finally, the way in which the whole research question is treated must be weighed.

## **Perceptions**

In corroboration of previous research (Kouyoumdjian et al., 2003; Wynaden et al., 2005; Youssef & Deane, 2006), the informants in our study also associated mental ill health with feelings of shame and stigma. In many of the interviews, terms like madness and being considered crazy or insane were brought up. Most informants claimed that they “knew” that mental illness was just like any other somatic illness, but people in their community or from their country of origin thought a person was insane if they went to see a psychiatrist or psychologist. Moreover, informants spoke of mental ill health in terms of normal life crises. However, when such an event became ‘serious’ or when neither the person nor his or her relatives were able to manage the situation they consulted a psychiatrist. According to some of our informants, a step toward ‘insanity’ had then been taken and the boundary between normal and abnormal had been crossed. The way informants explained that they utilised mental health services for serious conditions correlate with studies investigating hospitalization for mental disorders among immigrants. A Swedish four-year cohort study among

second-generation adult immigrants found that this group had a higher risk of being hospitalized, but only for psychotic disorders (Leão et al., 2005).

Furthermore, people were described as going through periods of depression or anxiety but that was considered to be normal and not an issue for psychiatry. It was, however, accepted as a reason to seek out social services, since most of the underlying causes for the crisis were of a social nature. Informants spoke of bad housing situations, high unemployment rates, and Rosengård as an insecure place in which to live. The last claim, however, was highly dependent on which neighbourhood in the borough people were living in. Finally, the matter of spirit possession was mentioned in some of the interviews. Psychological distress was at times attributed to possession by djinns, and in fact religion appeared to play a large role in dealing with various mental problems (Al-Krenawi & Graham, 2000; El-Islam, 2008; El-Islam, 1982; Johnsdotter et al., 2011).

### Treatment strategies

Instead of seeking psychiatric care, individuals turned to a range of treatment strategies that were apparently connected to how conditions were perceived. For normal life crises, support from family and social network was described as very important. This way of dealing with problems has since long been confirmed in research (El-Islam, 1982; Kleinman, 1991; Kouyoumdjian et al., 2003). The support could consist of speaking with or comforting friends and family members, and helping them with matters of daily life. The support might also take the form of offering someone a job. One man described how he had been invited to spend time helping his friend in his shop in times when he was feeling depressed. He was tired and weak and did not really want to go out, but the offer from his friend had been helpful. Furthermore, social support might also include arranging a marriage for an ill family member. Such an arrangement was described in a couple of interviews, but seemed to be controversial and to the best of our knowledge has not yet been investigated (this strategy is elaborated in the Further Research section). Finally, religion and faith was cited as alternative treatment options. Faith was described as having great value in times of distress, but major religious leaders, such as imams, were also portrayed as having the role of a psychologist. If a condition was thought to be due to possession by spirits, people turned to exorcists, who, we were told, could be found in large numbers in Rosengård.

## The research question

As many other similar studies investigating the utilisation of mental health services by immigrants in Western countries, our study was to some extent based on a vulnerability approach. The underlying assumptions were that immigrants have the same need of psychiatric care as non-immigrants, although perhaps in different forms. It was, therefore, presumed that mental disorders are invariable categories, independent of context. Finally, the vulnerability-approach led to seeing social network and support in faith and religion only as treatment options and not as factors promoting resilience which they may be (Peres, Moreira-Almeida, Nasello, & Koenig, 2007; Rutter, 2000).

Within the naturalistic paradigm data are viewed as stemming from an interaction between the inquirer and the data sources (Lincoln & Guba, 1985). By asking questions implicitly based on the above-mentioned presuppositions, data will take a certain shape. By asking why people do not seek medical treatment for mental illnesses, informants might take for granted that this is the norm and the picture of psychopathologized immigrants is thus upheld. If the research question had been formulated in terms of resilience, investigating why immigrants seem to be more resilient than people in the host society, we would probably get a different outcome.

Therefore, phenomena often need different levels and disciplines to be understood as thoroughly as possible, and this is most likely also true for the research on mental health care utilisation. There seem to be significant gains in the addition of a resilience perspective, underscoring the need for interdisciplinary research.

## Resilience

As we have seen in the background section, the theories concerning resilience are neither simple nor uncontroversial. Paper IV was a first attempt at applying the perspective of resilience to the issue of utilisation research, so that one look for vigour rather than weakness. It is not that one perspective is right and the other wrong, but the complexity of life enables us to understand people and situations in numerous ways. The residents of Rosengård demonstrated a low utilisation of mental health services compared to estimated needs. Paper I suggested that underlying causes for this may include shame, stigma, and lack of suitable health care resources. We also found that people may have less need of mental health services where mental distress is perceived as normal life crises rather than medical states. The question remains whether this perception could be a sign of resilience. When we searched for other signs of resilience in the material, we discovered

that factors we considered treatment strategies could also be seen as factors promoting resilience and thereby averting ill health. The predominant view sees immigrants as vulnerable, due to their often disrupted life trajectory. However, this should not always be taken for granted. First, immigrants have moved to new countries for different reasons, and not all of them have been exposed to war or trauma. Second, there are studies demonstrating that certain immigrant groups actually have better mental health than the majority population of the receiving country (Bhugra & Jones, 2001; Ortega et al., 2000). By applying Hacking's idea of the looping effect, we see the risk of immigrants internalizing the picture of being vulnerable and weak. If, instead, we refocus our attention on previously unrecognized resources, the looping effect might turn around the other way and promote resilience.

### About medicalisation

The investigation of perceptions of mental ill health among people whose country of origin lies outside the Western world showed a picture quite different from concepts established in Western psychiatry.

This alternative approach opens up the possibility of cultural critique in which we can use descriptions of other cultural characteristics to reflect self-critically on our own culture. In this act of reflection, common sense can be disrupted and assumptions reexamined (Marcus & Fischer, 1999).

In exploring the perception of mental ill health among immigrants it became clear that people in a multicultural neighbourhood treated psychological distress as a normal life crisis rather than a medical condition. In the light of this one may look at the so-called medicalisation process in Western society. The term medicalisation refers to the process by which human conditions and deviance are defined and treated from a medical perspective. In so doing the field of medicine extends to areas that were earlier considered non-medical, such as obesity or certain sexual behaviours (Conrad, 2007). Both the resilience perspective and those who oppose the medicalisation process react towards how

A swelling conglomerate of businesses and professions, institutions and agencies, from medicine to pharmaceuticals, from insurance industry to the mass media, turn handsome profits by assuring us that we are in the clutch (or soon will be) of any number of emotional, physical, or behavioural maladies. (Saleebey, 2006, p. 2).

The medicalisation debate has challenged psychiatry's notion of what is a disorder and what is normal (see Furedi, 2004; Horwitz & Wakefield, 2007; Kutchins, 1999; Summerfield, 2004). From such a critical perspective we might rather ask whether non-immigrants overuse psychiatric care, rather than immigrants underutilising it.

### **Doing research with interpreters**

Conducting research in a multicultural context means that the researcher must sometimes work with interpreters. We realised that the involvement of an interpreter would allow us to reach individuals who otherwise may have been inaccessible due to language barriers. However, we also found this involves methodological issues that one needs to take into consideration. By reviewing and comparing the different transcriptions of the interpreter's version and the translator's version of the same interview, we were able to identify several aspects that the interviewer was not aware of while conducting the interview. In the Pashto interview there was a significant conversation going on between the interpreter and the informant that the researcher was not part of. The interpreter gave evaluative comments and tried to make the informant answer the questions "correctly". Furthermore, the language skills and vocabulary of the interpreter seemed to be inadequate, both in Swedish and in Pashto. According to the translator, the informant even taught the interpreter a few new words. After reviewing the independent translation of the Pashto interview, the translator was asked to comment on the proceedings. First of all, he explained that the interpreter and the informant had different dialects, which affected the conversation since these dialects acted as strong class markers. Moreover, the translator also found that the interpreter acted impolitely and arrogantly towards the interviewee.

### **Implications**

Authors talk of "correct translations" as a goal for the interpreter (Patton, 2002; Squires, 2008). The assumption behind the use of such a term is that there is a "right" and a "wrong" in language and that understanding a conversation is not dependent on a person's cultural background.

Some practical issues are important to discuss, one should not, however, uncritically adopt "technical fixes" in the belief that they will confer rigour (Bourdieu et al., 1991). In our interviews we found for example, that matching interpreter and informant with respect to age, sex, and country of origin did not seem to guarantee a good outcome.

Several authors have emphasized the value of considering the epistemological approach of the researcher, and generally they agree that the interpreter is a part of the production of research data (Squires, 2009; Temple & Edwards, 2002; Temple, 2002; Temple & Young, 2004; Wallin & Ahlstrom, 2006). However, it should also be recognised that interpreters and informants are human beings and the language is dynamic. Some investigators seem to feel that technical fixes can solve problems with the interactions that may occur in interpersonal encounters between informant, interpreter, and researcher. For instance, Squires (2008) suggests that "if the translator and participant come from the same country but have different class backgrounds, the translator will not allow this difference to interfere in communications with the participant" (p. 269). Notwithstanding an interpreter's professional status and qualifications, the fact that he or she is perceived as a bearer of a certain culture, ethnicity, or religion may affect the informant in an interview situation in a way that is neither under the control of the interpreter nor the researcher.

Working with interpreters offers new possibilities for research: the group of potential informants enlarges and it becomes possible to reach specific groups with certain experiences who otherwise would remain inaccessible. By devoting time to the issue, the complexity of conducting qualitative research with interpreters became clearer. Using detailed checklists in order to improve methodological rigour may not resolve this complex issue, although it may give rise to a false sense of credibility in data.

### **Immigrant children with mentally ill parents**

In agreement with the findings of previous research, the children in our study expressed difficult circumstances they were living under as a consequence of their parents suffering from mental illness (Cowling, 2004; Mordoch & Hall, 2002; Östman, 2008a). They were anxious about the ill parent and they felt that they had to take on great responsibility for family and household since the parent did not have the capacity to care for everything. However, the mental illness of a parent was not their only concern, and in some cases it was far from the most significant one (Kessler et al., 2010; Oyserman, Bybee, & Mowbray, 2002; Tebes et al., 2001). Every child we interviewed had their own story to tell, and every story had its own special context. In a single interview a child could express concern, anxiety, guilt, and sadness, and yet also convey hope, strength, and a sense of being in control.

As others have previously recommended these children should get special attention and must be listened to in order to get their needs satisfied (Mordoch, 2010; Östman, 2008a). Nevertheless, we also concur with those who disapprove of highlighting only risk and vulnerability among this group of children. Based on theories from childhood sociology, Gladstone et al. (2006) have argued that seeing children as passive and ‘unfinished’ persons is an ethnocentric and typically Western point of view. The aforementioned assumption underlies much research on the mental illness of parents. To extend this notion to children and treat them only as ‘invisible’ or ‘at risk’ hinders them from expressing their opinions on the kind of support they need. It is, therefore, important to let children speak for themselves about their situation. The children in our study showed strength and maturity. Several of them made us realise that we should not take for granted that living with a parent who is mentally ill is exclusively a problem.

Even though ours was not meant to be a comparative study, we found some aspects of the data that most likely were the result of children having an immigrant background. However this was not explicitly discussed in the interviews. First, immigrant children could be especially vulnerable, since several of them are from countries where war is ongoing and may involve their relatives and friends (Walker, 2005). Also, they live in families where an ill parent might have to navigate an unfamiliar welfare and healthcare system, sometimes with the added difficulty of a language barrier. Second, several informants proudly declared that they were well-behaved, never went out late, and carried considerable responsibility for the household. This could be the result of them looking upon the researcher as a representative of the authorities, and therefore they felt obliged to explain that they were not like the ‘typical’ inhabitants of the area, i.e., they were not ‘bad’ immigrants.

# REFLECTING UPON METHOD

In this section, issues related to method and epistemology will be considered. Strengths and weaknesses involving design, data collection, and analysis, as well as trustworthiness and the value of intuition in research, will be discussed.

## **Overall design**

The overall design of this dissertation was a naturalistic inquiry. The advantage with such an explorative design is that it is easier to investigate issues that emerge along the way, as opposed to designs where the procedure is determined beforehand. Since the researcher is not locked into the examination of predetermined variables, naturalistic inquiry is especially suitable when dealing with unanticipated or unintended outcomes.

Bourdieu's (1991) ideas of epistemological vigilance are well-adapted to naturalistic inquiry. He suggests that approaching the field with one's "theoretical heritage" will not be enough to move forward in research, as it would be tantamount to making science out of common sense. To render unconscious thoughts and assumptions conscious so that one can break with them should be the primary task of research. The aim of naturalistic research is to present segments of situations in the informant's life. Therefore, as in all qualitative research, generalization or "truth statements, free from both time and context, are not possible" (Lincoln & Guba, 1985, p. 38).

## **Informants, recruitment and data collection**

### Paper I

The informants selected in the first study (Paper I) were between 18 and 65 years of age and lived or worked in Rosengård. The composition of the population of the borough was reflected in the background of the interviewees. The largest groups of immigrants in Rosengård came from the Middle East and former

Yugoslavia, and that was also true of most of our informants. With these broad inclusion criteria, the group of informants was so diverse that general conclusions were difficult to draw. On the other hand, a diverse group of informants is appropriate when attempting to collect rich material from many different contexts. "Maximum variation sampling will usually be the sampling mode of choice. The object of the game is not to focus on the similarities that can be developed into generalizations, but to detail the many specifics that give the context its unique flavour" (Lincoln & Guba, 1985, p. 201).

The first study employed the snowball method to recruit informants (Lincoln & Guba, 1985). The method is described as suitable for hard-to-reach people (Bernard, 2006), which we thought would be the case when we began our data collection. We knew that the topic could be perceived as sensitive among inhabitants in the borough and many people would not wish to participate. Our experience turned out to be just the opposite. When asked, people were happy to take part, and in some cases it felt as if the informants had waited for the day they would get the opportunity to speak out. Either the picture among professionals is exaggerated (which seemed to be the case in Paper III, elaborated below), and the shame and stigma associated with mental ill health might not be as strong as supposed. Alternately, as several informants explained, there is a large difference between talking to a person from one's own community and talking to a Swedish researcher, since in Sweden there is nothing to be ashamed of: mental ill health is 'normal'. Therefore, they appeared not fear any stigmatisation in speaking openly in our interviews.

The key informants in the chain referral method are important as in a sense they determine the direction of the sample (Bernard, 2006). Such informants were primarily immigrants holding professional positions in which they got to meet various groups of people. There is always a risk engaging this kind of key informant as there might be unknown relationships, power issues, or other implicit factors disturbing both the recruitment process and interview outcomes (see Berreman, 1962).

## Interpreter in research

### Paper II

The study on conducting research with interpreter was intended as a broad illustration of methodological issues that need to be considered when working with interpreter, not as a definite analysis of the qualifications of interpreters in general on the basis on two interviews. Furthermore there is no guarantee that the linguistic choices in a translation are "better"; it is yet another interpretation.

However, we deemed the translator of the Pashto interview as more qualified. Also the fact that the translator had more time for deliberation compared to the interpreters, could be regarded as an indication that the former's version of the interview was more accurate than the interviewer's account. Finally, another issue that has rarely been addressed in the literature is that of the opinion of the interpreters themselves. Researchers discuss how interpreters should and should not work, how they should conduct themselves, and what they should know. Interpreters are often referred to as if they were instruments in the hands of the researcher, who also decides how this instrument should be used (Edwards, 1998). On the other hand, the situation is sometimes described in the opposite way, in terms of an independent interpreter who is beyond the control of the researcher (Kapborg & Berterö, 2002).

The opinion of interpreters is not discussed in Paper II. We did, however, conduct two interviews with interpreters on how they viewed their own role. They were eager to defend the profession and constantly referred to the importance of adhering to ethical practices, according to the booklet *Good Manners of Interpretation* (Kammarkollegiet [the Legal, Financial and Administrative Service Agency], 2004), containing regulations and guidance for all translators and interpreters, authorized and non-authorized.

## Recruiting the children: gatekeeping

### Paper III

Several researchers (Lindsay, 2005; Patrick, Pruchno, & Rose, 1998) have discussed the issue of recruitment problems in research studies. Most of them concern recruiting participants for quantitative survey studies. The problem is often a matter of informants not wanting to participate. In our study the situation was different, since the potential informants were never asked. The issue of gatekeepers has generally received little attention in the literature, even though it is presented as a common obstacle one must deal with (Hood, Kelley, & Mayall, 1996; Sharkey, Savulescu, Aranda, & Schofield, 2010). In nursing science the phenomenon is referred to as "clinician gate-keeping" and defined as "the process whereby healthcare providers prevent access to eligible patients for research recruitment" (Sharkey et al., 2010, p. 363).

Recruitment problems regarding children have been discussed as part of a larger discourse concerning research practice with children and young people (Hood et al., 1996; Morrow & Richards, 1996; Sallnäs, Wiklund, & Lagerlöf, 2010). The growing interest in research on children is, in turn, an indication of increasing interest in the research field of childhood sociology, which appeared

in the mid-1980s. The sociology of childhood breaks with the dominant notion of children as essentially dependent, incompetent, and vulnerable. One of its key theses is looking upon children as social actors with the right and the competence to speak and be heard (Christensen & Prout, 2005; Sallnäs et al., 2010). To carry out such research, however, has proved to be challenging and has raised several methodological and ethical questions (Christensen & James, 2000; Morrow & Richards, 1996). One such challenge is the role of gatekeepers, a function with a two-fold implication. On the one hand gatekeepers are important in order to protect children and their integrity. On the other they can constrain children from making their voices heard. In our study, which had undergone careful ethical consideration and also obtained approval from the Regional Ethics Review Board, the parents had to give their consent for the children to participate. The main problem in our study was not that the parents acted as gatekeepers, since most of those who were asked to participate gave their consent. Instead the closed gate appeared higher up in the “hierarchy of gatekeeping” (Hood et al., 1996). When trying to ascertain reasons why professionals did not want to assist the researchers in the recruitment process, the main reason given was not to protect the children. Rather, professionals were afraid of asking the parents, since mental illness was regarded as “such a sensitive topic”.

In research on children, it is difficult to balance the child’s right to be heard with the child’s right to be protected. Regarding the recruitment process in our study, we concluded from the interaction with professionals that it was not that children’s rights were being protected, but that the children were restrained from being heard.

One weakness in our study was that we did not get to speak to children whose parents were suffering from mental ill health but were not getting treatment. We only encountered parents who had been diagnosed and were receiving treatment for their mental illness. Since the perception of mental ill health varies considerably it would have been of interest to investigate the life situation of children with parents who were not yet in treatment.

### Interviewing children

Several methodological issues arise regarding interviewing in general. How do we know in what way the informant perceives the researcher? Researchers may inhibit the informant from being outspoken. How do we know if what informants are saying about their actions corresponds with what they are actually doing? What processes do our questions initiate in the interviewee’s mind? Perhaps informants change their opinions during the course of the interview? When informants and

researchers come from completely different backgrounds, how do we know that they are talking about the same thing? The terms being used may refer to our 'different realities'.

Are there special difficulties in interviewing children? There are some who identify themselves with the sociology of childhood who have argued strongly that children should be seen as competent individuals, just like adults. Accordingly, there would be no need for specific methods in researching children's experiences (Christensen & James, 2000). We agree that children should be seen as authorities on their own lives. However, the researcher must be open to interview techniques for engaging individuals on different levels of understanding. In the end we cannot expect capacity of an adult and a ten-year-old child to be the same (Greene & Hogan, 2004). Another aspect that childhood sociologists have criticized is that children are often seen as a homogenous group, so that children in a specific age group can all be interviewed in the same way (Christensen & James, 2000). In studying immigrant children, we found that conducting interviews with children could be as different and as challenging as interviewing adults. While some children were happy to speak with us and talked a lot, others remained quiet and had difficulties participating in a semi-structured interview where the informant is expected to partly steer the direction of the interview.

### **Processing data**

Data processing is often described as an activity carried out at a certain stage of a predefined process, which is ordinarily after collecting the data but before writing a report. In fact, the analysis starts from day when launching a new research project. "I have found that my analysis goes on even if I am not actually working with the data. Insights and new ways to look at the data arise while I am at work at other things" (Glesne, 1999, p. 131) This quotation illustrates the difficulty of describing the exact data processing phase of a research project. The analysis of the data for the first study did not even conclude after the article was written (Paper 1), which resulted in the rest of the studies in this dissertation.

When one has rich narratives from an interview sample based on maximum variation, it is difficult to narrow categories. As described earlier, there were often contradictory opinions about certain topics. For example, regarding support by Imams in times of mental problems, some informants compared imams to psychologists, while others claimed they had no understanding for mental illnesses whatsoever. Not only does the data reflect divergent views, but the informants live in different contexts, and these are often lost in the written report, mainly because of the limited amount of words allowed.

For the third study we met each of the eleven children for one concluding interview. They generated a substantial amount of material that was then sorted into categories, a common way of organizing and reconstructing interview data. In hindsight, a more narrative approach would have been desirable, since it would have opened up the possibility of gaining deeper insight in how the children themselves experience their life situation in their special context (Larsson, Sjöblom, & Lilja, 2008). The procedure of reducing the material into categories is not particularly sensitive to processes, contexts, and the dynamics in the lives of the informants. All the children had different experiences that were closely related to a broader context. The complexity of their life stories easily became lost in the data processing phase, and even more so in the reporting of the results.

### Intuition

One important element in naturalistic inquiry is the utilisation of tacit knowledge (Lincoln & Guba, 1985). This is a treacherous area in research since it lacks any possibility of being scrutinized scientifically. It was, however, intuition that led us to study the role of interpreter the in research.

The word intuition comes from the Latin *intuitus*, which means "the act of gaining knowledge from direct perception or from contemplation" (Tedlock 2006). The term is often used as an antonym for analytical reasoning and has not been recognized in traditional scientific research, except in philosophy, where it has been a subject of inquiry (DePaul and Ramsey 1998). Schön (2003) has explored the boundary between 'hard' and 'soft' thinking by looking at the role of observation in professional practice, and the limits of academic thinking. The theory/practice issue is central to his research as he studies things that professionals 'know', but cannot put into words. In many professional situations including research to a certain extent, people rely more on unconscious knowledge than on theories and formulas learnt during their formal education. However, this is rarely recognized in scientific publications. Schön argues that cases often dismissed as intuition or creativity are based on experienced phenomena. People solve problems based on previously encountered, similar challenges, perhaps from a completely different source. He refers to Thomas Kuhn, who

calls such processes "thinking from exemplars". Once a new problem is seen to be analogous to a problem previously solved, then "both an appropriate formalism and a new way of attaching its symbolic consequences to nature follow", — "follow", that is, from reflection on the similarity earlier perceived. (Schön, 2003, p. 183)

These ideas resemble those of Linde (1993), though they are expressed in different terms. For Linde intuition is an expression or reaction to what we have unconsciously registered earlier in accordance with our coherence system. Valerie Janesick (2001) has advocated for recognition of intuition and creativity in qualitative research:

Doctoral students often discuss with me the ways in which intuition has manifested itself in their research projects. They often want to go further in exploring how they came to probe in interviews, how they decide to go back to social settings on given days, or how they revisited their interview transcripts. It is this phenomenon, the act of using intuition and creativity in the research act, which made me think about how much we are missing if we don't explore the importance of both intuition and creativity. Historically, over the past 40 to 50 years, we have been writing and thinking a great deal about the design of qualitative research projects and about technique. Although design and technique are critical, I want to shift this conversation to go beyond technique. (p. 532)

Science only confers authoritative status on specific modes of inductive and deductive reasoning. However, few would disagree that “there is no creativity in science, indeed, in any domain of creative activity, that does not entail intuition” (Laughlin, 1997, p. 6). Intuition came into play over the course of the whole research project, and was partly how the different studies came to be. Most obvious was the aspect of intuition in Paper II that studied the role of interpreters in research. Before a second opinion on the interpretation of the different interviews presented in the study was received, the researcher had a fairly clear sense of what the outcome would be. That picture was solely based on the interviewer's intuition and was only later confirmed by a more conventional ‘scientific’ method.

### **Trustworthiness**

Naturalistic inquiry engages different techniques to meet the criteria of trustworthiness in data. One such criterion is prolonged engagement. The idea behind prolonged engagement is that the researcher should be familiar with the society and culture in which he or she is carrying out a project, in order to minimize the risk of distortion that might otherwise creep into the data. There is no answer to what that means in an exact time frame. Prolonged engagement is relative and depends on the design, circumstances, and extent of the study. During the four-year duration of this research project a considerable amount

of time was spent in Rosengård. Prior to the research project all authors of the different papers had worked or conducted research in the area. It is, however, only some ten informants we have met more than once and the data collection for Paper I and III differed regarding informants and setting.

Since Paper I was a part of a larger research project there was a possibility of triangulating sources, methods, and investigators (Lincoln & Guba, 1985). Triangulation is another technique of building trustworthiness in research by investigating the object from different angles. Various researchers investigated aspects of mental ill health in Rosengård, using alternative methods and sources. The whole group of researchers working with both qualitative and quantitative data had regular meetings and seminars discussing both the study process and outcome.

Peer debriefing is yet another way to establish credibility. It "is a process of exposing oneself to a disinterested peer in a manner paralleling an analytic session and for the purpose of exploring aspects of the of the inquiry that might otherwise remain only implicit within the inquirer's mind" (Lincoln & Guba, 1985, p. 308) For doctoral students, peer debriefing takes place in different settings and in regular seminars.

Member checking, both formal and informal, is described as one of the most crucial techniques for establishing credibility. This strategy implies that results, interpretations and conclusions are tested with members of the groups in which data originally were collected. It mainly took place in an informal way during the course of investigation both for Paper I & III. The dictum from one interview was repeated to another informant and the outcome discussed. We also reviewed the interpretations of the interviews with key informants and professionals in the area.

Finally, the trustworthiness of our findings is enhanced by the presentation of direct quotations and comparisons with previous research in the field.

## SUMMARY AND CONCLUSION

The overall aim of this dissertation was to study the putative underutilisation of mental health services in a multicultural context.

By using a naturalistic approach, according to which the direction of the research develops as it proceeds, three seemingly disparate areas were investigated: perceptions of mental ill health among adult residents and professionals in a multicultural neighbourhood, experiences of immigrant children living with a mentally ill parent, and the theoretical understandings and assumptions underlying research concerning underutilisation. In addition, the methodological issues concerning the role of interpreters in research were elaborated.

The question concerning utilisation of mental health care among people living in a multicultural setting is complex. Immigrants are not a homogenous group, and while some individuals may be greatly affected by their socio-economic situation, others are preoccupied with relatives still struggling in their country of origin. Cultural differences strongly affect certain people in their encounter with a new country. Others have adapted to the culture of the host country or are navigating between different cultures without experiencing many problems. Not only are immigrants a heterogeneous category, but academics studying underutilisation of mental health services vary in perspective and ways conducting their research. Moreover, working together with an interpreter has shown itself to be an important but delicate issue.

Hence, we are confronted by a multi-layered context that is hard to define. This complexity should be kept in mind, whether one is engaged in doing research or in clinical practice.

The present thesis has sought to demonstrate how various perspectives can broaden the understanding of a research issue. Even though the issue of resilience has only been sparsely elaborated, it has offered an additional way of thinking about utilisation research and the study of immigrant children living with a mentally ill parent. As our findings indicated, vulnerability should not be taken for granted.

There is, however, a danger in highlighting the resilience perspective: it may be invoked as an argument for reducing resources in the health care system. If people can 'manage' because of resilience, financial savings may as well be enacted, a cynic might say. The resilience perspective is not about ignoring problems, illness, and adversity but about seeing the glass as half full rather than half empty. Research including both perspectives offers a broader range of alternatives with regard to where and when to allocate resources, whether it be for treatment, socio-economic support, or the strengthening of factors promoting resilience.

## FURTHER RESEARCH

### **Investigating needs**

As this study has highlighted, there appears to be a gap between estimated and perceived needs among immigrants. Most studies concerning utilisation of mental health care are based on the supposition that there is a greater prevalence of common mental disorders among migrant groups, and thus increased needs of psychiatric care (Fassaert et al., 2009). There is now clear evidence that certain immigrant groups have a higher prevalence of schizophrenia. It is also established that migration constitutes an important risk factor (Bhugra & Jones, 2001; Cantor-Graae & Selten, 2005; Kinzie, 2006). Regarding the association of non-psychotic disorders and migration, studies have yielded contradictory findings (Bhugra, 2004; Kinzie, 2006; Lindert et al., 2008). In specific contexts of some populations, the prevalence of certain mental disorders has been shown to be higher compared to non-immigrants (de Wit et al., 2008; Lindert et al., 2008). Other studies have found that immigrants have the same or less risk of developing mental disorders as people in the receiving country (Bhugra & Jones, 2001; Ortega et al., 2000).

In several articles the low utilisation is established by referring to other studies comparing service use between minorities and the host population (Kouyoumdjian et al., 2003; Wynaden et al., 2005; Youssef & Deane, 2006). Such comparisons are rarely adjusted for cultural differences, which assume that all people have the same need of mental health services. Another approach has been sought to determine need through specific instruments. One such instrument is the Jarman index (Aoun et al., 2004; Jarman, 1983), which was explained in the background section. There are voices critical of the assessment of needs (Aoun et al., 2004; Joska & Flisher, 2005) and others sometimes take need for granted within a predefined Western clinical context (Summerfield, 2004; Watters, 2001).

The study of perceived needs among immigrants is an under-researched area. New studies investigating needs of immigrants beyond pre-defined frameworks must be carried out in order to better understand the issue of utilisation of mental health care, and provide for actual needs.

### **Resilience**

In Paper IV a first attempt of highlighting a downplayed aspect in the area of utilisation research was made. Resilience may be an additional key to understanding the utilisation of health care among immigrants.

It would be of interest to conduct a study in the same multicultural context as paper I, investigating such aspects of resilience as experiences of risk, good outcomes and protective factors and their relation to utilisation of mental health care. Furthermore, a study of immigrants and non-immigrants may be of value in assessing resilience in different groups.

Finally, the mental health of immigrants in different generations might show if resilience is changing from generation to generation, and whether this is also true of the non-immigrant population.

### **Arranged marriages and mental ill health**

Several informants highlighted the importance of support from family and social network. Mental ill health was described as taken care of within the family or a larger social network. This caring also could include arranging a marriage for the ill person.

The Egyptian-based psychiatrist El-Islam (2008) describes how the social support could work in Arab communities:

Traditional families help their sick members to reintegrate by arranging suitable marriages, employment and leisure time occupation. In effect, such families carry out a number of social services provided by the welfare state in many non-traditional societies. . . Elders arrange marriages for all their young relatives, including schizoid and schizophrenic individuals whose emotional lives would likely handicap them in 'love' marriages. (p. 625)

At the same time it is widely known that mental ill health is closely associated with insanity (Endrawes, O'Brien, & Wilkes, 2007; Kirmayer et al., 1996; Youssef & Deane, 2006). Also, informants in our study confirmed that mental ill health is taboo and people would never imagine having their sisters or daughters married to a man with mental ill health.

On one hand, people “take care” of family members suffering from mental ill health by arranging marriages; on the other hand, they would never let their own family members marry a person with mental ill health. Apparently, this is a contradiction, but, as far as we know, this kind of relations has not been explored in research before. The aim of a future study could thus be to investigate the phenomenon and highlight possible tensions or conflicts between different perspectives.

# POPULÄRVETENSKAPLIG SAMMANFATTNING

Avhandlingens titel är *Psykisk ohälsa och mångfald – forskning kring mänskligt lidande och resiliens i en mångkulturell kontext*.

En konsekvens av den fortsatt höga migrationen runt om i världen är att samhällen i allt högre grad blir mångkulturella. Den internationella migrationen innebär utmaningar för välfärdssystemen vilket bland annat är det tydligt inom området stöd och behandling av psykisk ohälsa. Det innebär även en utmaning för invandrare som kommer till samhällen som kan skilja sig fundamentalt från hemlandet vad gäller samhällsorganisation, värderingar, klassifikationssystem etc.

Utgångspunkten för avhandlingen var en kartläggning från år 2005 som visade att befolkningen i den mångkulturella stadsdelen Rosengård, i relation till skattade behov, konsumerade häften så mycket psykiatrisk vård som Malmös övriga befolkning. Det övergripande syftet var att studera den förmenta underkonsumtionen av psykiatrisk vård i en mångkulturell kontext.

Metoden följde en naturalistisk undersökningsmetod, vilket innebär att studien i sin helhet inte är designad i detalj på förhand. Istället ses forskningen som en process som utvecklas efterhand som forskningsarbetet fortskrider. Detta innebär konkret att första delstudien var designad när avhandlingsarbetet inleddes, medan resterande tre har emanerat ur forskningen under resans gång. Syftet med första delstudien var att undersöka synen på psykisk ohälsa bland människor som bodde eller arbetade i stadsdelen Rosengård i syfte att finna möjliga bakomliggande orsaker till den låga konsumtionen av psykiatrisk vård. Vi fann en rad olika förklaringar som kan indelas i tre grupper: synen på psykisk ohälsa, behandlingsstrategier och frågor rörande de premisser som den första delstudien utgick ifrån. Först och främst handlade det om synen på psykisk ohälsa. De

flesta av våra informanter beskrev att psykisk ohälsa var nära sammankopplat med skam och stigma och ofta uttryckt i termer av galenskap. Vidare beskrevs tillstånd av mentala problem i form av livskriser snarare än som ett medicinskt problem. Alla tillstånd som beskrevs som hanterbara utan att man behövde söka psykiatrisk vård var normala livskriser. När situationen blev ohållbar och varken personen själv eller dess omgivning kunde lösa svårigheterna vände man sig till psykiatrin och personen hade därmed passerat gränsen till galenskap. Normala livskriser ansågs alltid ha förklarliga orsaker som till exempel socioekonomiska svårigheter. Psykiska problem kunde även förklaras i form av besatthet av andar.

Om man inte upplever ett tillstånd som medicinskt är det således naturligt att använda sig av andra behandlingsstrategier. För att lösa normala livskriser beskrevs familj och socialt nätverk som oerhört viktigt. Även tro och religion angavs som en behandlingsstrategi. Dels ansågs tron stärkande i sig genom att kunna skänka personen inre lugn i tider av stress. Dels beskrevs stödet mer konkret i uppsökandet av religiösa ledare som ibland liknades vid psykologer. Om orsakerna till de psykiska problemen förklarades som besatthet av andar, var det till andeutdrivare man vände sig.

Den tredje förklaringen handlade om forskningens upplägg och forskarnas perspektiv. Likt många andra studier som handlar om underkonsumtion bland invandrare baserades den första studien på en grundtanke om sårbarhet. På grund av omständigheter som följer hela migrationsprocessen, och eventuella traumatiska upplevelser som föranleder den samme, anses invandrare som en särskilt sårbar grupp med en ökad risk för att utveckla psykisk ohälsa. Forskning kring detta är dock mångfacetterad och det finns studier som visar på ökad risk, men även de som framhåller minskad risk för invandrare att drabbas av psykisk ohälsa. Då vi antog att det faktiskt fanns en underkonsumtion av psykisk ohälsa förutsattes det således att människors behov går att skatta likvärdigt oavsett bakgrund samt att psykisk ohälsa yttrar sig likvärdigt och kräver samma typ av behandling oavsett kontext. Genom att utföra intervjuer implicit styrda av ovan angivna antagande, formas även empirin på ett särskilt sätt. Om vi i stället hade infört resiliens-perspektivet, kring vilket ett resonemang är utvecklat i fjärde delstudien, och undersökt varför invandrare verkar behöva mindre psykiatrisk vård än övriga befolkningen i Malmö hade resultaten förmodligen blivit annorlunda. Med detta perspektiv har vi även insett att faktorer såsom socialt nätverk och tro, vilka vi enbart kategoriserade som behandlingsstrategier i studie ett, även är erkända faktorer för att stärka resiliens.

I delstudie tre, som undersökte livssituationen för barn till föräldrar med psykisk ohälsa och invandrarbakgrund, fanns det en likaledes förutfattad mening om att barnen skulle leva under svåra omständigheter. Detta blev också delvis bekräftat i våra resultat. Många av barnen bar en extra börda som inte enbart kunde förklaras av direkta faktorer av föräldrarnas mentala tillstånd utan även av indirekta konsekvenser av social karaktär såsom fattigdom, bostadsproblem och skilsmässa mellan föräldrarna. Samtidigt som barnen beskrev svåra situationer var det många som visade på styrka, glädje och hopp om framtiden. Även i denna studie upplevdes därmed resiliensbegreppet vara värdefullt för att i analysen göra rättvisa åt det empiriska materialets spännvidd.

Slutligen innehåller denna avhandling en metodologisk studie rörande forskning med tolk. Efter att ha fått en second opinion av två översättare kring två intervjuer utförda med olika tolkar, kunde vi dra slutsatsen att det finns många metodologiska frågor som kräver diskussion och övervägande i intervjustudier utförda med tolk. Mycket av existerande litteratur ger praktiska förslag kring hur man kan undvika misstag i processen. Dessa inkluderar dock sällan förutsättningen att tolken inte är ett instrument utan en människa, som påverkar det mellanmänniska mötet. Genom att ignorera känsla och intuition och enbart följa tekniska rekommendationer finns det en risk att forskare får en falsk upplevelse av trovärdighet i forskningsresultatet.

I och med att samhällen i allt högre grad blir mångkulturella står vi ständigt inför nya utmaningar. Detta arbete har visat på stor komplexitet vad gäller området konsumtion av psykiatrisk vård i en mångkulturell kontext, en komplexitet som bör tas i beaktande oavsett om det handlar om forskning eller kliniskt arbete.

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