

# THE PRODROMAL PHASE OF WHAT?

# A Metapsychiatric Analysis of the Prodromal Phase of Schizophrenia

Anna-Karin Neubeck



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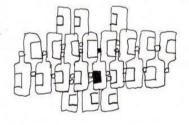
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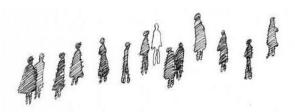
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# INTRODUCTION

This thesis is about the general concept of prodromes of psychosis, and more specifically prodromes of schizophrenia. Prodromes are a relatively new term used both in practical psychiatry as well as in research, and are often defined as the very earliest signs of a coming psychosis. The phenomena are by some experts seen as having great importance and as enabling new psychiatric breakthroughs in early identification as well as innovative psychiatric treatment methods. But the phenomena are debated and involve several ethical and practical questions. The concept is also philosophically compound since it is not plainly a psychiatric concept, relating to phenomena that are not necessarily psychiatric conditions. I will in this thesis try to explain and analyse why the issues are challenging.

Psychosis is a generic psychiatric term for a mental state in which thought, perception, cognition, behavior and inner control are severely impaired. The symptoms are not only linked to a particular state but are mainly associated with diagnoses such as schizophrenia, affective disorder (manic-depression), drug-induced psychosis, organic psychosis, and so forth. The prevalence of all types of psychosis is about 1-5%, and the lifetime prevalence of schizophrenia is about 0.5-1%.

Preventing and lessening severe psychotic illness has always been a major interest for psychiatric research. In the past twenty years or so, however, the research on early psychosis has in fact exploded.<sup>3</sup> Reports have appeared concerning all areas of early psychosis, such as detection, identification and social risk factors, as well as understanding neurodevelopment, gene-environment interactions and develop novel treatment possibilities, to name but a few. There have also been several studies about aetiology, pathology and treatment outcome in schizophrenia.

When it comes to the definition and identification of the prodromes of psychosis, it has been up until today argued that there are many important psychiatric implications. It has been said that there is a possibility of preventing and/or mitigating the actual psychotic episode if medical treatment is started already in the prodromal phase. As an example, early identification is said to have the potential to reduce both psychosocial and

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<sup>&</sup>lt;sup>1</sup> The organic and drug-induced psychotic states are excluded from this study since they are likely to be mainly treated by other medical specialities than psychiatry. The term "organic mental disorder" was eliminated from DSM-IV because it incorrectly implied that other mental disorders do not have a biological component. (Kaplan & Sadock, eds. 1995, p. 681)

<sup>&</sup>lt;sup>2</sup> DSM-IV 1994, p. 282. The numbers differ some between studies because of different use of inclusioncriterion as example.

<sup>&</sup>lt;sup>3</sup> A search on PubMed shows that 4016 articles were published on the topic of schizophrenia in 2007. www.pubmed.com/results (www.nebi.nlm.gov/sites/entrez) 2007-12-27. A Google search on the topic of schizophrenia shows more than 12,000,000 hits 2007-12-27.

biological effects of a severe psychiatric condition. The prodromes are by some considered early signs of schizophrenia and have thus been regarded as possible prediction entities. New theories have also led to pharmacotherapeutic recommendations for targeted interventions since it has been claimed that specific treatment will have a positive effect on the outcome of schizophrenia relapses. Other clinical trials have shown effects of antipsychotic medical treatment for persons who are prodromally symptomatic and considered at high risk of developing schizophrenia. Some researchers believe that negative progression in schizophrenia in general and other negative biological processes may be a result of delays in treatment, and it has been said by some to be a more positive prognosis the earlier the treatment is started, which is an argument why early treatment is by many regarded as important. On the other hand the findings have in some studies turned out to be so non-specific to schizophrenia that it has been argued that they hardly tell anything about coming psychosis and least of all schizophrenia.

Since there are a great number of studies on what occurs prior to a first-episode psychosis, different ways of understanding the theories have developed. I will in this thesis claim that researchers offer exceptionally variable interpretations of these theories. These interpretations lead to different potential uses, which I have examined. I have also analysed how strong the relation is between the concept of prodromes and the definition of schizophrenia, leading to a discussion about different interpretations and their validity. This involves reasoning about the risk of including false positive patients in treatment interventions and if treatment is given, side-effects, stigma and the risk of losing dimensions of the patient's life-world.

Metapsychiatry as part of the field of philosophy of science and psychiatry is a combination with a great potential. Psychiatry is young as a science and there are a great number of questions that are still, and maybe always will be, discussed and in need of adjustment. In all sciences, it is a challenge not to settle for unfounded truths, and so of course is the case with psychiatry. Most basic definitions and diagnoses in psychiatry must be viewed from different perspectives to form a dynamic science. In fact, very few definitions or diagnoses in psychiatry are firmly set or founded on uncontroversial natural scientific knowledge: only a few are even based on durable or comprehensive knowledge. Of course, one could discuss the definition of truth and knowledge but that is not my intention in this study.

Metapsychiatry instead seems to offer a significant perspective on the field of labelling in psychiatry, such as "prodromes of psychosis", especially prodromes of schizophrenia.

<sup>&</sup>lt;sup>4</sup> McGorry, et al. 2002; Miller, et al. 2003; Schooler, et al. 2005; Ruhrmann, et al. 2007

<sup>&</sup>lt;sup>5</sup> See for example Møller 2001; <a href="www.schizophrenia.com">www.schizophrenia.com</a> 2007-12-27: "The first step in getting treatment for schizophrenia is getting a correct diagnosis. This is important to do quickly because research has shown that the sooner you get diagnosed and treated, the better the long-term outcome."

# **AIM**

The empirical material used for interpretation, analyses as well as reasoning in this thesis is an interview study including eleven patients at a psychiatric special unit. The information obtained in the interviews is complemented with information from the patients' medical records. I have also analysed a choice of current published research on the "prodromal phase of psychosis" as well as "schizophrenia" which is used as theoretical material.

The original aim was to answer the following question:

1 – Is it possible to identify so called prodromes, as described in some research publications, prior to a first episode of psychosis?

The interpretation is hypothetical, the analysis is theoretical and carried out from the perspective of philosophy of science. I analyse and discuss some different definitions of schizophrenia as well as different definitions described as markers for a coming psychosis, especially schizophrenia. I have allowed myself to apply two of them on the empirical material, the interviews and information from medical records. The following texts are used for the "prodrome interpretation":

- Jane Edwards and Patrick McGorry's Implementing Early Intervention in Psychosis: A Guide to Establishing Early Psychosis Services, especially Chapter "Prodromal phase".6
- Paul Møller's The Phenomenology of the Initial Prodrome and Untreated Psychosis in First-Episode Schizophrenia. An Exploratory Naturalistic Case Study.

The question could soon be answered in the affirmative. It was indeed possible to find prodromes or *prodrome-like phenomena* prior to an episode of psychosis among the patients interviewed in this study. This led to the revised aim of answering the following question:

# 2 – How are these phenomena interpreted and experienced by the patient?

In this approach I instead used a phenomenological interpretation on the same material. The method is qualitative and the analysis is phenomenological and subject-oriented.

<sup>&</sup>lt;sup>6</sup> Edwards & McGorry 2002

<sup>&</sup>lt;sup>7</sup> Møller 2002 (Including: Møller & Husby 2000, Møller 2001)

Deriving from the diversity of the results of these two different interpretations, a third aim emerged, a more causally oriented one:

# 3 – What explanations of these phenomena can be given?

On the basis of interpretations presented I then discuss some different explanations and consequences that can be derived from different interpretations of the phenomena.

# DISPOSITION

This thesis is divided into five parts, **A, B, C, D,** and **E. Part A** contains ethical questions and theory; presenting a framework for the interpretations and discussion. For example: how "schizophrenia", "psychosis" and "prodromes" are defined in diagnostic manuals? First and foremost I have focused on the psychiatric framework since it is primarily within a psychiatric practice the concepts are going to be used and patients will be treated. But this part also includes a more everyday understanding of related definitions, showing a general context in which these concepts are functioning. In this part I also present the essential concept, namely the "prodromal phase of psychosis".

**Part B** is a presentation of the method I have used for collecting the empirical material, the interviews and medical records and also a presentation of the techniques used for the two interpretations: the psychiatric and possible "prodrome"-, and the phenomenological interpretation, which I use for my analysis and discussion.

**Part C** contains the case analyses, showing the two different interpretations of the empirical material. In Chapter 4 I present the results from the initial aim of answering the question: 1 *Is it possible to identify so-called prodromes, as described in a number of psychiatric research publications, prior to a first episode of psychosis?* I have used psychiatric theory presented in Part A. The result is a possible scenario and a realistic example of how to use some definitions of the "prodromal phase of psychosis".

In Chapter 5 I present another possible but rather different picture of how to interpret the same material. This answers the second question, aim 2: *How are these phenomena interpreted and experienced by the patient?* This interpretation is done with a method focusing on the subjective and phenomenological information given by the patients in this study.

The results differ and I discuss the differences in **Part D**. I have presented my conclusions, as well as analysed how to explain these prodrome-like phenomena (aim 3). Further I have tried trauma theory as an understanding of these patients' sufferings and symp-

toms. In Chapter 7 I also continue to discuss the differences in how to interpret and understand these phenomena. Last in Part D I have put a New Summary, including my subjective reflections on dilemmas analysed in the thesis. Part E contains references.

#### **METAPSYCHIATRY**

Psychiatry is a complex and multifaceted field of research. My entering this field without being a psychiatrist has led to numerous misunderstandings about several dimensions of my thesis, including my aim, my motive and my agenda. To resolve these, and if possible reduce the number of further misunderstandings, I would like to explain what kind of study this is, and what kind it is *not*.

This thesis is a theoretical metapsychiatric study, the intention being to analyse and discuss phenomena used in psychiatry at a metalevel of understanding. The study is not psychiatric and not medical. The intention has been to analyse a specific phase defined within psychiatry, namely the "prodromal phase of psychosis", both from the perspective of philosophy of science, using psychiatric knowledge, and from the perspective of the patient, using phenomenological method. These different analyses led to the third aim namely a possible explanation of and discussion regarding the phenomena included within the concept.

The aim of the study has also changed over time: circumstances emerged which made it necessary to adjust the aim towards a more subject-oriented, or in other words a more phenomenological one. The study was not designed to try out a special list of prodromes of psychosis or a special interview guide regarding prodromes of schizophrenia. It is instead an open, qualitative study based on subject oriented interviews as a mean of analysing - metapsychiatrically - what was found in this phase. The patients were to lead the interviews and decide what it was most adequate to mention. I have tried, all through the interviews, to maintain an openness towards the patients in letting them decide what to talk about and what to focus on. If the intention had been to use interviews as a way of detecting early signs of schizophrenia, the study would have had a more psychiatric approach. That is also why I have not used any prodrome assessments; using such assessments would have lessened the possibility of a more all-embracing and subject-oriented understanding of the phenomena. For these reasons, it was not the most important focus, for the hypothesis of *this* study, which diagnosis, if any, these persons eventually received. A specialized psychiatric clinic considered them at risk of developing psychosis, which meant the patients were in a state which agreed with the condition in focus for newly published "prodrome research". That was enough for me to try my hypothesis.

From here on my study differs from the treatment given to the patients at the clinic in that I use, in a hypothetic way, research that the clinic did not regularly use. The clinic was treating the patients according to a specialized method and I analysed the material with new research about the prodromal phase. Two parallel processes. Again, the clinic did not use knowledge about the prodromal phase as a diagnostic tool although they were familiar with the concepts. But since it has been argued that new results can be used as prospective entities for intervention, I wanted to analyse this phase in depth. This included an interest in finding out what information was given, and possible to obtain from the patients at this specific time. The patients included in this study were admitted to the psychiatric specialist units with tentative diagnoses of a coming psychosis; if they had had psychotic experiences they were at an early stage of the psychotic process.

The aim has never been to check up on or criticize the work of a specific psychiatric clinic. Some have suggested that it was so since I have done a follow-up on diagnoses at the end of the concluding section. But this is done as an illustration of what actually happened to the patients included in this study, the real persons. The follow-up has also been done to ascertain the variety of diagnoses, and to show that I actually interviewed many of these patients prior to the time when they got a diagnosis including psychotic symptoms; a state which concurred with definitions of the prodromal phase of psychosis. In that sense I have succeeded in my initial aim. So, were any of these patients diagnosed with the specific psychotic diagnosis of schizophrenia? Yes, some of them were which means that I succeeded in my aim again.

The analysis I have made of these patients, interviews and medical records has been used to illustrate two lines of theoretical reasoning. Could these patients be regarded as being in the prodromal phase of a coming psychosis? That question is why I have used as new knowledge as possible about the phase to see if the patients in this study would – hypothetically – meet the criteria for being in a prodromal phase of schizophrenia. After the interviews, I had no further contact with the patients or their psychiatrist regarding their treatment. My theoretical reasoning has not interfered in the treatment of these patients. Nor have I any reason to question the treatment or the diagnoses at the clinic. My theoretical analysis has been parallel with and isolated from the treatment of these real persons. Instead, the analysis and the discussion are purely theoretical and hypothetical.

# JOINT PROJECT BETWEEN NORWAY AND SWEDEN

This project has been made possible through grants from the Northern Norway Regional Health Authority, Nordlandssykehuset Vesterålen and Josef and Haldis Andresen, legacy in Baerum, Norway.

The practical work was performed at a local hospital in Northern Norway. There were at the time of the study several specialized clinics at the hospital, three of them psychiatric: one adult, one child and one inpatient clinic. The hospital was the base for the region, adult psychiatric centre – *Distrikt Psykiatriskt Senter DPS* – that consisted of five units. Two units were located at the hospital: one specialized day unit and one inpatient unit. Three more inpatient units were located in the region. All of these five units were part of the specialized psychiatric healthcare system in the region. It was possible to include patients at all units in the centre in this study.

The hospital was the only hospital in the region. The region is a typical Northern Norwegian one, both geographically and culturally. There were about 35,000 inhabitants in the area at the start of this study.

One of the main concerns of the psychiatric centre has been the treating of different psychotic states. Two of the inpatient units were at the start of this project exclusively treating patients with psychotic symptoms. Specialized education has been given to the staff focusing on the complexity of psychosis. This was done within the regime of SEPREP – Senter for psykoterapi og psykososial rehabilitering ved psykoser. This is only one of several efforts focusing on patients with psychotic symptoms.

The specialized adult psychiatric care has been organized and functioning in the region for over twenty years. A main focus has been the care of patients with psychotic symptoms; evaluating and research on the clinical and organizational work has been a focus of interest for the leader of the centre. In an all-embracing project plan, established by the leader, the demand for clinical research on the work done at the centre is specified. This study is part of that research demand.

The project is part of the doctoral programme, at the Division of Health and Society, Department of Medical and Health Sciences, Linköping University, Sweden. Two professors are supervisors for the project: Lennart Nordenfelt, professor of philosophy, specializing in the concept of health, and Lisbet Palmgren, professor of psychiatry, specializing in schizophrenia.

# PART A – ETHICS, THEORY AND FUNDAMENTAL CONCEPTS



# 1 Ethics

# **ETHICAL EXAMINATION**

Regional komité for medisinsk forskningsetikk Helseregion Nordnorge in Tromsø has evaluated and approved the project. The reference number of the project is 200106457-3/IAY/400.

*Datatilsynet* in Norway had no objections to the implementation of the project. The reference number of the project is 2001/4406-4 MOF/-.

The local department of the patient organization *Mental Helse* has not had any objections to the implementations of the project.

Every patient has been asked individually and has given his or her written letter of agreement to take part in the study. The agreement allows information to be collected from the adult psychiatric clinic, the whole DPS and the child psychiatric clinic. A request for permission to talk to relatives was granted.

The patients were asked about participating in the study by the doctor responsible at the clinic. No patient had been in contact with the project leader prior to agreeing to take part in the study. In some cases the patients wanted more information about the project than was given by the therapist responsible, and then this information was given by me as the project leader.

No information was registered about patients who declined to take part in the study, and such information was never handed to me as the project leader. The ethical committee in Norway does not approve of such registration. This is why I have not been able to make a full drop-out analysis.

# ETHICAL CONSIDERATIONS

I have chosen to corroborate key facts told in the interviews by means of sources of information available to the project, principally medical records. This does not mean that every detail is confirmed or verified. Details are in some cases even deliberately changed because of ethical considerations and confidentiality. In view both of the fact that the ex-

periences reported were so extreme and of the fact that this is a theoretical study, I saw no reason to explore every detail in depth. Nor was there any reason to verify details from any other perspective than metapsychiatry, since this study has no medical, juridical or even police intentions. Nor was it possible for me to discuss specific details told in the interviews with the therapists. The information given in the interviews was confidential and I had no alternative but to listen to what was told about the patients and read what was written in the medical records.

After going through two patients' medical records thoroughly, deeper analyses of the texts in the medical records were reduced, also for ethical reasons. Details did not contribute to the analysis to an extent that made further analysis necessary. Medical records have always been used, though, as a source of complementary information about core and summarizing facts in the interviews.

All patients were considered able to take part in the study by their psychiatrist. There was no question, in any case, that the patients could not handle an interview, or that an interview or taking part in the study would be a risk to their health. However, as a safety measure it was noted in every patient's record that they were taking part in the study, and every patient was also offered extra therapy sessions with their therapist if they wanted.

The interviews were recorded, all except one. After the transcriptions, that were made by me, and in two cases by a secretary at the clinic who obeyed the same ethical rules as me, the transcriptions were made anonymous. No names, age or personal identification numbers were written. The recordings are locked in a safe at the clinic, as is the key to the codes of the patients that I used during the analysis. Some recordings are also locked in a safe in Stockholm since much of the analysis was done there. The written texts or information copied from the medical records have either been locked in the safe or made anonymous.

I have also occasionally been given information about the patients by taking part in the daily work at the clinic. I have as far as possible tried to use such information with restriction, but sometimes the information led me to look deeper into the medical record for further information. Sometimes this led to valuable new information, sometimes the information was dropped. I have also been able to discuss some of the ethical questions and considerations with my closest colleague at the clinic, as far as possible without exploring any personal information about the patient. Sometimes it has even been necessary to discuss the information with this specific colleague, for example in the case of questions about psychiatric or ethical details told to me in the interviews or some information that I found in the medical record or heard while working at the clinic. I consider this a security measure for the patients, since I am not a psychiatrist and wanted to be sure I did not misinterpret any information. The information handed to my professors has been anonymous, but in the initial material there are still some details.

To summarize, I have all through the reading of the medical records, interviews and analysis been interested in phenomenological information. All information has been part of my analysis but not always shown in the written results. I have throughout tried to consider ethical aspects of the informants' integrity, since the information handed to me has been both very intimate and private. Some details, of importance for the analyses, I have included in changed form to avoid direct references to the patient. If someone for instance had been abused by a close family member I have deliberately changed the relationship but kept it as a near relative or family member. I have also changed age, names, workplace, interests and ethical background, but changed them to something corresponding and comparable. I have not however, changed their sex. And again – this study is purely a theoretical analysis with these patients as elucidative examples. After the interview I had no further contact with the patients or their therapists. My theoretical analysis has been parallel with and isolated from the treatment of these real persons.

I have chosen to call the persons interviewed *patients* when they have been under treatment in psychiatric care, which means in fact patients. When I analyse the stories in the phenomenological interpretations I have most often chosen to call them *informants*.

# 2 General psychiatric theory and introduction of fundamental concepts

In this thesis I have attempted to analyse a phase prior to when a patient is diagnosed with psychosis. Since most research focuses on early phases of schizophrenia I have in this theoretical chapter chosen to elucidate definitions merely related to the definition of schizophrenia: those of schizophrenic psychosis, prepsychotic condition and prodromes of schizophrenia. To clarify the theoretical framework I have chosen to have two chapters as introduction: one on the paradigm of psychiatry and the other on the aims of the definitions. Naturally there are several other interesting definitions and themes but I have chosen to restrict this analysis to these.

Definitions of specific concepts by theorists of central importance for this thesis are found in this part: when it comes to schizophrenia, there are textbook theories, definitions of schizophrenia in the diagnostic manuals, and so forth.

# THE PARADIGM OF PSYCHIATRY

The field of psychiatry is complicated by the large number of different scientific or maybe even prescientific interpretations that exist. No area – in psychology or psychiatry – is dominated by one theory, one paradigm or one scientific foundation. This will of course affect how the theories are to be understood and which methods are used in practice. This has also led to countless methods of treatment in psychiatry and psychology. Schizophrenia, and then of course early signs of schizophrenia, constitutes just one obvious example of this complexity.

Different types of expertise start from different scientific theories and paradigms, which means they have different understandings of the world. As an example psychologists, with a cognitive-behaviour theory as a basis, have little in common with more biologically focused neuropsychiatrists, who base their theories on a more natural-scientific paradigm. Another example is offered by psychoanalysts, who, with the more psychody-

namically oriented theorists, understand psychological reactions through how interactions and representations of objects affect the individual. Specialities such as psychology, psychiatry and sociology can be called preparadigmatic since different researchers and practitioners, believe in different scientific foundations, even within the different scientific spheres.

Since different paradigms are to be found in psychiatry and none of them have explained why a psychotic episode occurs in an all-embracing way, nor exactly what the condition is, the situation with the prodromes of this condition is complex. The situation is intricate because of the many recent attempts to identify earlier and earlier signs of these psychotic conditions and the wish to start treatment as early as possible. This means that the margin between what is considered to be healthy and therefore normal and what is considered to be pathological is changing. Individuals with light and small changes can be included in an early schizophrenia group whereas a couple of years ago they were defined as normal healthy persons. There is a risk they will be transferred to a group of sick patients or a "soon to be ill" group (at risk mental state). The group of "the normal" is reduced and the development can lead to a smaller and smaller number of supernormal individuals, an exclusive group of people without any difficulties or weaknesses. This could lead to many adverse effects both for the community and for the individuals. Psychiatric theories of today are based on very few uncontroversial natural-scientific facts but rather on conditions defined by humans, changing over time - and controversial to many.8 A community and its members choose what should be defined as healthy and pathological and as normal and not normal. There are few objective and reliable truths, and many theories and opinions are value-laden.

I believe increasing knowledge and scientific findings could lead to a divided field of psychiatry. It is not hard to believe in, on the one hand, a more biological part of psychiatry, working with for example brain damage caused by physical and biological changes in the brain as well as neuropsychiatry, and as a part of general medicine; on the other hand, a more nonbiological part of psychiatry with the focus on psychological changes and difficulties experienced by the patients, and maybe also a more philosophical psychiatry dealing with more existential difficulties and reflections. This could lead to a clearer differentiation between medicine and "psychiatry", the borderline between which is today often confused and incomprehensible. It could lead to psychiatry, being not one scientific field but instead including several fields of expertise: psychiatric medicine, psychology and philosophy for example. I do not by this mean that those belonging to different disciplines

<sup>&</sup>lt;sup>8</sup> See further Kirk & Kutchins 1992; Kirk & Kutchins 1997; Hacking 2000; Foucault 1973; Hallerstedt 2006; just to mention a few.

will have less chance to understand one another in the future but I believe there are clear benefits with clarifying distinctions as well as interdisciplinary understanding. In recent years there have been many attempts to explain certain phenomena of experience with cross-disciplinary theories, for example psychodynamically and biologically comprehensive theories. And hopefully there will be even more tolerant attitudes towards multiexplanatory theories in the future, including equally cause, effect and understanding. These are some of the reasons why I see a great need for discussing the purpose and methods of psychiatry. Discontinuous proposed in the future of the reasons who is easier to be a great need for discussing the purpose and methods of psychiatry.

# THE AIM OF THE DEFINITIONS

Psychiatrists in the Western world today are using two diagnostic manuals for psychiatric conditions: *The Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition, called DSM-IV,<sup>11</sup> and The ICD-10 *Classification of Mental and Behavioral Disorders*, *Clinical descriptions and diagnostic guidelines*, called ICD-10.<sup>12</sup> Both manuals have been translated into the Nordic languages. These two manuals are used in most psychiatric practice as well as most psychiatric research. The aim is to offer a possibility of unified communication and international understanding of psychiatric conditions. The manuals are seen as tools for diagnosis, communication, research and finding treatment recommendations for different psychiatric conditions.<sup>13</sup> In reality many practitioners are also obliged to diagnose their patients for other reasons such as insurance. If the patient does not get diagnosed, the clinic will in many cases not get paid for the treatment. So these manuals define the work in psychiatric practice and are often necessary as well as restricting many practitioners in psychiatry today.

The mentioned diagnostic manuals have evolved to clarify recommendations and to be a helpful guide to clinical practice.<sup>14</sup> The manuals are deliberately atheoretical since there are no unified theories as to why or how psychiatric conditions occur.

<sup>9</sup> For example Cozolino 2002

<sup>10</sup> For a further analysis see Neubeck 2003

<sup>&</sup>lt;sup>11</sup> APA, DSM-IV 1994 (I will in the following use the ref DSM-XX)

<sup>&</sup>lt;sup>12</sup> WHO ICD-10 1997; WHO ICD-10 1999 (Norweigan version) (I will in the following use the ref ICD-10, 1997; or ICD-10 1999). I have used the Norwegian version of the manual, since I wanted to use the same version as the therapist at the clinic when discussing the patients included in this thesis. I have also included the English version in the analysis. I have also used the most updated version on <a href="https://www.who.int/classifications/icd">www.who.int/classifications/icd</a>

<sup>13</sup> DSM-IV 1994, p. xv

<sup>14</sup> DSM-IV 1994, p. xv

A basic issue is to which definition of health these psychiatric definitions are related. Of course the effects on diagnosing, especially in the initial phases of a pathological process, are vast. An existing and well-known problem taken up in the diagnostic manuals is how to separate normal and healthy reactions and conditions from pathological ones. How can one know when a normal reaction *develops* into something pathological and psychiatric and should be treated, and if suffering should be used as a criterion of pathology even if the suffering is not direct and immediate in some conditions defined by psychiatry? An example of such a condition is manic depression, where in an early manic phase the patient can merely feel euphoric, happy and capable. As mentioned there is no biological laboratory or other test that can confirm a psychotic condition, except organically induced conditions.

The question of why, how and when to diagnose, label and/or characterize different mental states is a core dimension in the ongoing discussion in psychiatry and psychology as well as in different fields of philosophy. Examples can be shown from many perspectives and one example is the vast criticism of the Freudian theory of labelling and interpretation of different neurotic behaviour as linked to the different symbols and inner drives of the child. For example little Hans' neurotic relationship to handbags.<sup>15</sup>

The criticism has concerned both the absurdity of defining a handbag as a symbol of the vagina and the lack of a feminist perspective in Freudian analyses in general. Carol Gilligan, Nancy Chodorow and of course Simone de Beauvoir offer examples of such feminist criticism. The question of diagnosing was also the core dimension in the antipsychiatric criticism in the 60s, 70s and 80s. Thomas Szasz, Ronald Laing and Michel Foucault among others criticized in different ways the use of diagnoses as a tool of psychiatry and the attendant failure to discover the real causes of mental disorders, or mental reactions as some prefer to call them. As soon as a state of mind, a behaviour, a disorder or a suffering is categorized it will lead to different effects and consequences, partly depending on the motivation for the label or diagnosis and how it is used. The American Psychiatric Association has taken an openly atheoretical stand in their manual of mental disorder, DSM-IV, as a result of many of these criticisms, trying to make diagnoses a tool for practical categorization only. Whether they have succeeded or not is of course also debated.

All societies have throughout history in different ways been mystified by and in need of labelling different mental expressions. Psychiatric diagnoses have also been reported as being used for different purposes, for instance as a way of disclosure, by defining a group as normal and excluding the not normal. Psychiatry has because of this often been given

<sup>15</sup> Freud 1955

<sup>16</sup> Beauvoir 1977; Gilligan 1982; Chodorow 1989; Hekman 1995

<sup>&</sup>lt;sup>17</sup> Szasz 1961; Laing 1961; Laing 1966; Foucault 1972; Foucault 1973; Foucault 1975

great social power. A diagnosis can lead not only to exclusion from society or to social stigma, but also to obtaining needed assistance in terms of economic, medical and/or practical support. Many societies do treat the undiagnosed differently from the diagnosed and today many persons with a psychiatric diagnosis experience how societies hold them responsible for their failures: for example in insurance discrimination, in work discrimination or in that persons with a psychiatric diagnosis often are presented in the media as violent and dangerous to other people. 18 This touches several difficult philosophical questions, for example the issue of personal responsibility as well as whether a mental disorder "is done to you" or something "you do", also the essential dichotomy in psychiatry of individuality versus generality. 19 Is a mental disorder a part of the subject or not? Regarding the schizophrenic prodrome, there are several difficulties, for example since there are still discussions on causation and the "mother term", meaning "psychosis" or "schizophrenia". There is disagreement on schizophrenia and there is of course disagreement on the causation and outcome of prodromes of schizophrenia, (more on this in Chapter: "The Prodrome Context"). So, since there is still uncertainty as to the cause of schizophrenia, it is only possible to treat the symptoms. But similar symptoms can have different causes and sometimes be treated differently. If the causes of schizophrenia were found it would be possible to aim interventions at this cause or these causes. Today schizophrenia symptoms are seen as the disorder itself, since there is no corresponding knowledge on causation.

Of course, it has been argued that it is positive and simplifying that a majority working in psychiatry have a universal system. Important for this thesis is that working with a diagnostic system such as DSM-IV or ICD-10 excludes certain understandings of many conditions central to this thesis merely because the manuals do not consider causes. The condition is regarded as a condition within the individual – and the individual is the one treated and seen as having the problem. With the focus on observable single symptoms often listed, the individual is separated from the contextual factors in the manuals. <sup>20</sup>

Since this study's aim is to analyse a very early stage of a process, the discussion and analysis concern – deliberately – all functional psychotic states. As the stage I have chosen to focus on it is not theoretically or practically yet possible to separate different psychotic states from each other. This may cause some discussion about the difference between the schizophrenia prodrome – most focused on in recent literature and research – and other psychotic early stages. I am aware of this discussion but have chosen the more open defi-

<sup>18</sup> Sadler 2004 (in: Radden (ed.) 2004), p. 164, see also many examples in the press like the killing of the minister Anna Lind in Sweden.

<sup>19</sup> Sadler 2004 (in: Radden (ed.) 2004) p. 164; Fulford 2006, pp. 289-315

<sup>&</sup>lt;sup>20</sup> In DSM-IV's multi-axes system there is a possibility including psychosocial and environmental problems, with axis IV. The different axes are seldom used in public presentations though.

nition of "prodromes of psychosis" and therefore included a wider definition of psychosis.

As will be described in Chapter "Prodrome Theory", there has been an urge for early identification of the psychotic process. This since early identification is assumed by many to lead to early treatment possibilities and – proposed by many – to be a way to better prognosis. Yet with this go different problems, mainly with false positive patients and, if treatment is given, side-effects, and the new research field of prodromes has started a discussion about for example ethics and the reliability of all definitions included in the field, like schizophrenia and psychosis, not to mention prodromes. There are still many questions unanswered and many questions in need of a thorough analysis. This thesis is just a small contribution to such an analysis.

As is also shown in Chapter "The Prodrome Terminology", there has emerged a differentiated terminology for this early stage and early phenomena. In this introduction I do not wish to distinguish between different researchers but instead give an overview and an introduction to the definitions.

The different connotations of psychosis can exemplify some different interpretations and meanings. On the one hand there have been attempts to define psychosis as a biological process, or a neurobiological feature in some individuals, or even a specific localization in one chromosome, even cellular particles, or viruses etc.<sup>21</sup> On the other hand psychosis has been defined as a defence mechanism, psychodynamically defined as a result of interaction with external circumstances.<sup>22</sup> Social-constructivists have interpreted the diagnoses as being interactive with the individuals getting them.<sup>23</sup> The diagnoses and the individuals, according to their ideas, are part of an ongoing process involving interaction between the individual and the person making the diagnosis, and where the context plays a role.<sup>24</sup> There will be potential for many discussions about the diverse interpretations used both in research and practice. In this chapter I have attempted to present a short overview of the most commonly used definitions central to this thesis. The psychodynamic definitions of the features in the prodromal phase are more specifically analysed and discussed in the Chapter 8 "Discussion". But I would like to emphasize that there are clinics and practitioners that have chosen not to define psychosis as anything else than a "crisis" in an attempt not to enter the complicated field of cause and outcome, just because there is such a wide range of possible definitions of the term "psychosis". Two theoretically important practitioners are professor Jakko Seikkula of the University of Jy-

<sup>&</sup>lt;sup>21</sup> See further Chapter 3: "The Prodrome Context - Different definitions of schizophrenia".

<sup>&</sup>lt;sup>22</sup> Holi et al. 1999, pp. 654-660

<sup>&</sup>lt;sup>23</sup> Laing 1966; Foucault 1973

<sup>&</sup>lt;sup>24</sup> Hacking 2000 pp. 100-124

väskylää, Finland, who has discussed the hypothesis that the psychosis can be seen as a crisis, and professor Johan Cullberg, who has questioned the strict division into separate psychotic states.

# **CAUSALITY**

The concept of causality or causation denotes the relationship between one event (called cause) and another event (called effect) and the concept refers to the set of all causal or cause-and-effect relations. A cause is termed "necessary" when it must always precede an effect. This effect need not, though, be the sole result of the one variable. A cause is termed "sufficient" when it inevitably initiates or generates an effect. Any given cause may be necessary, sufficient, neither, or both.

The most influential analyses of causality (for instance Mackie 1974) emphasize that the term "cause" in both ordinary and scientific contexts normally refers to a *part of a sufficient condition* which is not in itself necessary for its effect. Mackie coins the expression "INUS-condition" for this kind of cause. This entails that a cause is generally a part of a complex condition. The condition termed "the cause" presupposes these other conditions for the effect to occur.

The idea of complex sufficient conditions is essential to this thesis. The causes of the sufferings described probably constitute only certain elements in a set which as a whole is a sufficient condition of the studied effect.

#### **PSYCHOSIS**

The concept of psychosis is phenomenological-psychological and no biological marker exists to identify the mental state, nor is there any internationally accepted definition that covers the full concept of psychosis.

The primary psychotic symptom is *delusion*, without which no psychosis exists, and the other main symptoms are:

- Hallucinations
- Disturbed behaviour
- Confusion or delirium.

There are different types of psychotic conditions: schizophrenia, affective psychosis and reactive psychosis, for example: and also many other mental states including psychotic symptoms, for example depression with psychotic symptoms. The uniting symptom for

psychosis is losing contact with reality, manifested in a difficulty in separating what are internal sensations and phenomena and what are external.

The definition of "psychosis" has always been problematic:

The term psychotic has historically received a number of different definitions, none of which has achieved universal acceptance. The narrowest definition of psychotic is restricted to delusions or prominent hallucinations. ... A slightly less restrictive definition would also include prominent hallucinations that the individual realizes are hallucinatory experiences. Broader still is a definition that also includes other positive symptoms of Schizophrenia. ... The different disorders in this section emphasize different aspects of the various definitions of psychotic. <sup>25</sup>

The diagnostic manuals for mental disorders DSM and ICD have made the diagnosing process operational, maybe at the cost of understandability. Earlier the definitions of Kraepelin were dominant with regard to schizophrenia, defined as dementia precox. It has always been an accepted fact that there is a diffuse border between normality and pathology and that there have been very few strict and clearly defined borders between different disorders. This needs to be borne in mind when defining earlier and earlier characteristics of different disorders. The definitions and the inclusion criteria have changed over time, probably more because of time changes and less because of scientific facts. There is also an uncertain line between misinterpretations and delusions, as between delusions and hallucinations.

The development of the condition can be seen as a process from the absence of symptoms to full-blown psychosis. Then one can define different phases of the process, starting with the prodromal phase, the phase in focus in this thesis. Other phases defined and used in the diagnostic manuals are the prepsychotic state, the early phase and the late phase of the psychosis. The three phases – prepsychotic, early and late phase – have mostly indications for medical interventions today and has little importance for the analysis in this thesis.

<sup>&</sup>lt;sup>25</sup> DSM-IV 1994, p. 273

# THE PRODROME CONTEXT – DIFFERENT DEFINITIONS OF

# "SCHIZOPHRENIA"

Literature and research present several definitions of schizophrenia and different interpretations lead to radically different consequences. Because such differences are central to the discussion in this thesis I would like to exemplify some diverse examples. Prodromes are related to different definitions of psychosis, mostly schizophrenic psychosis, which is why I have chosen schizophrenia to be the main concept in the presentation that will follow. It is of importance for interpretation of the prodromes whether cause and exclusion criteria are taken into consideration and whether genes, hereditary factors, biology or psychological experiences are presented as "components", "triggers" or "factors" in the schizophrenia process.

# SCHIZOPHRENIA AS AN ILLNESS DIAGNOSIS - ACCORDING TO DSM AND ICD

The two main diagnostic manuals used in the Western world, DSM and ICD, both use atheoretical definitions of "schizophrenia". "Schizophrenia" is described as a disorder or disturbance, containing a number of symptoms and with an undefined aetiology. No causal explanations are presented in DSM of schizophrenia; because of this atheoretical standpoint there is no recommended necessity to ask about earlier life events. DSM is on the other hand more likely to call attention to factors such as drugs and medicine as exclusion criteria and associated findings. It should be mentioned, again, that there are other axes in the manual that take social and historical factors into consideration.

DSM-IV classifies schizophrenia together with other psychotic disorders, and the disorders included in:

... this section are all characterized by having psychotic symptoms as defining features. Other disorders that may present with psychotic symptoms (but not as defining features) are included elsewhere in the manual. <sup>26</sup>

The essential features of schizophrenia are a mixture of characteristic signs and symptoms that have been present for a significant portion of time during a one-month period (or for a shorter time if successfully treated), with some signs of the disorder persistent for at least six months (Criteria A and C) according to DSM-IV.<sup>27</sup>

<sup>&</sup>lt;sup>26</sup> DSM-IV 1994, p. 273. The organic and drug-induced psychotic disorders are excluded from this study.

<sup>27</sup> Ibid., p. 274

Criterion A for Schizophrenia requires that at least two of the five items be present concurrently for much of at least 1 month. However, if delusions are bizarre or hallucinations involve "voice commenting" or "voice conversing", then the presence of only one item is required.<sup>28</sup>

This means that if you are hearing voices, and/or talk to voices in your head, that single symptom is enough for you to be considered schizophrenic.

DSM-IV presents associated physical findings in individuals diagnosed as having schizophrenia, and the authors mention different characteristic features that can occur. But it is questionable whether these features are just phenomena that may, for other reasons, be more common among individuals with schizophrenia. The authors conclude with a remarkable comment about the most common associated physical finding among the group of individuals diagnosed as having schizophrenia:

Most common associated physical findings are motor abnormalities. Most of these are likely to be related to side-effects from treatment with anti-psychotic medications.<sup>20</sup>

That means that according to DSM-IV the most characteristic physical finding in schizophrenia, and furthermore probably one of the most stigmatizing factors, is a side-effect of medication!

Schizophrenia is the main and most common disorder in the category F20 – F29 in ICD 10, other disorders included in the section are: schizotypal disorder, and paranoid disorder. In the introduction, in the Norweigan version of the manual, to the chapter on schizophrenia in ICD-10 it is stated the schizotypal disorder has many of the same characteristics as schizophrenia and is probably genetically connected to schizophrenia.<sup>30</sup> This indicates that ICD-10 considers schizophrenia and schizotypal disorder to be at least partially genetically correlated.

In ICD-10 it is possible to include the prognosis in the diagnosis. The numerical designations of the diagnoses use the last number to indicate the course: from F20.x0 – chronic – to F20.x9 – unknown course. ICD-10 does not discuss prognosis as much as DSM-IV but one may observe other diagnosis of acute and passing psychosis, F23, which has a more sudden start and transition which is seen to indicate a better prognosis, than a state that has a long and more sneaking start. ICD-10 describes schizophrenia and other schizophreniform disorders as having a long-lasting and sneaking start. The anamnesis discussed in this thesis often showed long duration of initial changes and sufferings.

<sup>&</sup>lt;sup>28</sup> DSM-IV 1994, p. 277

<sup>&</sup>lt;sup>29</sup> Ibid., p. 280

<sup>&</sup>lt;sup>30</sup> ICD-10 1999, p. 82, this is in the introduction to the chapter on Schizophrenia in the Norwegian version.

<sup>31</sup> Ibid., p. 81ff

DSM-IV states that the prevalence of schizophrenia is usually estimated to be between 0.5% and 1%.32 But:

Because Schizophrenia tends to be chronic, incidence rates are considerably lower than prevalence rates and are estimated to be approximately 1 per 10,000 per year.<sup>33</sup>

This is an interesting and important passage for my thesis. As is stated, schizophrenia tends to be chronic and the prognosis is pessimistic.

Most studies of the course and the outcome in Schizophrenia suggest that the course may be variable, with some individuals displaying exacerbations and remissions, whereas others remain chronically ill. Because of the variability in definition an ascertainment, an accurate summary of the long-term outcome of Schizophrenia is not possible. Complete remission (i.e., a return to full premorbid functioning) is probably not common in this disorder.<sup>34</sup>

The positive prognostic possibilities are not very strong according to this. Even though the authors do underline the difficulty involved in the definition of schizophrenia and the variety in study design and method, they do stress a weak prognostic probability of complete remission from schizophrenia.

According to DSM the negative prognosis and the dementia-like development are characteristic of schizophrenia and are used to distinguish schizophrenia from other psychoses. That means that prognosis is part of diagnosing. Schizophrenia is for DSM by definition combined with a negative prognosis, and patients with positive recovery will have their diagnosis of schizophrenia questioned. Hope of full recovery or at least a positive prognosis is decreased with the diagnosis of schizophrenia according to DSM. In the introduction to DSM the authors also discuss the need for a new understanding of psychiatric conditions. One possibility discussed is to consider the conditions as a continuum and not categories, which would make differences between conditions less harsh and settled and make the diagnosing process more dynamic and possibly also less stigmatizing.

The onset of schizophrenia can be abrupt or insidious according to DSM-IV, but:

The majority of individuals display some type of prodromal phase manifested by the slow and gradual development of a variety of signs and symptoms.<sup>35</sup>

<sup>32</sup> DSM-IV 1994, p. 282

<sup>33</sup> Ibid., p. 282

<sup>&</sup>lt;sup>34</sup> Ibid., p. 282

<sup>35</sup> Ibid., p. 282

The signs and symptoms listed in DSM-IV as prodromes of schizophrenia are:

- Social withdrawal
- Loss of interest in school or work
- Deterioration in hygiene and grooming
- Unusual behaviour
- Outbursts of anger<sup>36</sup>

Family members' concern is also mentioned in the text. Interesting is the terminology of signs and symptoms in the quotation above, which indicates that phenomena in the prodromal phase are seen as part of a pathological and ongoing process. They have the intensity of symptoms and can therefore be regarded as pathological, as a consequence also possibly exposed to treatment. An interpretation of this text is that the prodromal phase and its signs and symptoms are part of the schizophrenic process. The difference between the prodromal phase and schizophrenia is defined in terms of active phase-symptoms that mark the disturbances as schizophrenia according to DSM-IV.<sup>37</sup> According to DSM schizotypal, schizoid, or paranoid personality disorder sometimes precedes the onset of schizophrenia, but whether these personality disorders are simply prodromal to schizophrenia is not clear.<sup>38</sup> This of course widens the concept of the prodromal phase of schizophrenia according to DSM since the disorders mentioned above are much more severe than the prodromal signs listed earlier in the manual.

ICD-10 notes that a shorter or longer period of prodromal symptoms and behaviour can appear some weeks or months prior to the first psychotic symptoms. But, it is stated that because of the difficulty of defining duration these prodromal symptoms are not included as diagnostic criteria.<sup>39</sup>

Also important for the course is the actual onset, and according to DSM the onset has both pathophysiological and prognostic significance: the earlier the start of the process the poorer the prognosis. This is important for the patients in this study who had been abused and neglected in some cases from the time of birth. They had thus experienced phenomena related to these abuses from a very early age.

A variety of differential diagnoses are listed in DSM-IV, primarily psychotic disorders due to a medical condition and delirium. The interesting differential diagnosis for this

<sup>&</sup>lt;sup>36</sup> DSM-IV 1994, p. 282

<sup>37</sup> Ibid., p. 282

<sup>38</sup> Ibid., p. 280

<sup>&</sup>lt;sup>39</sup> ICD-10 1999, p. 84f; this is in the Norwegian version. In the latest version of ICD-10 published online at WHO, "prodromal" is only used in describing different phases in schizophrenia. http://www.who.int/classifications/apps/icd/icd10online/

study is maybe the diagnosis of Psychotic Disorder Not Otherwise Specified. This diagnosis may be made according to DSM-IV

/If/.. insufficient information is available to choose between Schizophrenia and other Psychotic Disorders (e.g. Schizoaffective Disorder) or to determine whether the presenting symptoms are substance induced or are the result of a general medical condition. Such uncertainty is particularly likely to occur early in the course of the disorder.<sup>40</sup>

The possibility that life experiences can lead to severe psychiatric symptoms is not mentioned. The only contraindications that are mentioned in ICD-10 are if obvious brain damage is proven, or if the person is under the influence of drugs or having an abstinence reaction.

According to many definitions schizophrenia indicates incurability, chronicity and disability. A patient diagnosed as schizophrenic has little chance of full premorbid function, to quote DSM-IV. According to the Social Department in Norway, the prognosis for patients diagnosed as having schizophrenia is full recovery in 15% of the cases, and approximately 20-30% of the patients will have at least one period of hospitalization and may be able to handle easy work if treated. In 50-60% of the cases one has to expect several relapses with severe impairment, but the patient can for a period live outside a hospital. In 10-15% of the cases the condition is so severe that one can expect full-time care to be necessary for the rest of the patient's life. The prognosis is dependent on treatment outcome and how early the intervention is started. Studies have shown that the prevalence of suicide is one of every 10 people with the diagnosis of schizophrenia.

#### **TEXTBOOK THEORIES**

I have chosen to present various definitions of schizophrenia that are known and used in both psychiatric practice and education and are commonly known to psychiatric personnel as well as to some extent the public.

The textbook definitions of schizophrenia I have chosen to present are professor Einar Kringlen's, defined in *Psykiatri*, professor Johan Cullberg's, presented in *Psychoses* and *Dynamisk Psykiatri* and an English version presented by Michael Gelder, Juan Lópes-

<sup>40</sup> DSM-IV 1994, p. 284

<sup>41</sup> Ibid., p. 282

<sup>&</sup>lt;sup>42</sup> Statens helsetilsyn 2000 p. 10 (Anna-Karin Neubeck (AKN) translation)

<sup>&</sup>lt;sup>43</sup> DSM-IV 1994, p. 280, (http://www.wrongdiagnosis.com/s/schizophrenia/prognosis.htm (2007-03-21) Schizophrenia Research at the NIMH)

Ibor and Nancy Andreasen, in *New Oxford Textbook of Psychiatry*.<sup>44</sup> I have chosen so since this is a present understanding of schizophrenia in the Western world today, showing something of how schizophrenia is understood by us as a society as well as by our medical services. I have also included some informational material available at the clinic, called Psykopp (Psychiatric Informational Material).

Schizophrenia is in the *New Oxford Textbook of Psychiatry* presented in general as a functional disorder, with diminution or absence of mental functions – negative symptoms – or the presence of an abnormal mental process, which includes delusions, hallucinations and formal thought disorder – positive symptoms.<sup>45</sup> Phenomenological understanding of the life-world of the patients is emphasized, though different interpretations of the various symptoms are rare in the text. The symptoms or features are described as being objectively observable features of functional impairment. It is described as being a dimension of subjectivity in the diagnostic process and the different features are primarily discussed as an individual problem for the patient. It is of importance for this discussion that the textbook points to the fact that much of the diagnostic process is influenced by the psychiatrist making the diagnosis.

For example there is the dimension of understandability: patients with schizophrenia are often difficult to understand because of abnormalities of the underlying thought. 46 Could it also be an inability of the listener to understand what is communicated? There are difficulties in the presentation of schizophrenia when it comes to cohering with the external world and other individuals; much of the presentation focuses on the single individual. The person diagnosed as having schizophrenia does not communicate according to set social norms and often communicates without the same consistency and context as other persons. But does that mean that schizophrenia is a disorder of not following social norms? And that the patient is communicating without the focus of understandability? That instead the patient may be focusing on his or her internal world? There is a possibility of considering the results of this study as indicating that some of the so-called inabilities in these patients have a dimension of focus on the inner world, and not on an abnormal inner world, just an individual and preoccupied inner world.

The textbook presents most of the symptoms as observable clinical features. In the introduction to the chapter on descriptive clinical features of schizophrenia it is stated that:

<sup>44</sup> Gelder et al. (eds.) 2006

<sup>45</sup> Lidle 2006 (In: Gelder et al. (eds.) 2006), p. 575

<sup>46</sup> Ibid., p. 573

The clinical features of schizophrenia embrace a diverse range of disturbances of perception, thought, emotion, motivation, and motor activity. It is an illness in which episodes of florid disturbances are usually set against a background of sustained disability. The level of chronic disability ranges from a mild decrease in the ability to cope with stress, to a profound difficulty in initiating and organizing activity that can render patients unable to care for themselves.<sup>47</sup>

Although no less than one-third of all patients with schizophrenia have relatively benign outcomes, in the majority the illness has a profound lifelong impact on personal growth and development.<sup>48</sup>

There are several aspects and difficulties to consider when talking about the course and outcome of schizophrenia as presented in the textbook. The textbook has presented an overview of studies on course and outcome in schizophrenia which shows a variety of reported rates of recovery or complete remission between 12% and 32%. <sup>49</sup> These figures are discussed in the text as methodologically difficult. There is, as shown in the above quotation, even with the diverse study results on course and outcome a strong tendency to consider schizophrenia a chronic illness.

It is also difficult to show the course of "natural schizophrenia" a subject also discussed in the textbook since there are few patients and even fewer cohorts of patients that are studied untreated.<sup>50</sup>

In the conclusion of the chapter on genetics and environmental risk factors for schizophrenia in the *New Oxford Textbook of Psychiatry* several significant risk factors are shown. The conclusion is that the sum of these factors could produce the psychotic illness.<sup>51</sup> Genes exert a probabilistic rather than a deterministic effect on the development of schizophrenia, and environmental risk factors appear to be necessary for the disease to become manifest in many, if not all, cases.<sup>52</sup> Psychological trauma is not mentioned as an exclusion criterion.

To be psychotic is by DSM defined as having delusions or prominent hallucinations without insight into the pathology of the symptoms. Johan Cullberg, in his book *Psychosis*, gives psychosis a descriptive and dynamic definition, designating it a phenomenological-psychological phenomenon. He describes the psychosis as a crisis, and underlines that there is no clear-cut difference between different diagnoses of psychoses and a psychotic and a non-psychotic condition, as well as the fact that there is also an uncertain boundary between experiences that we all have in the form of daydreaming and fantasy states that

<sup>&</sup>lt;sup>47</sup> Lidle 2006 (In: Gelder et al. (eds.) 2006), p. 571

<sup>48</sup> Jablensky 2006 (In: Gelder et al. (eds.) 2006), p. 619

<sup>49</sup> Ibid., p. 614

<sup>&</sup>lt;sup>50</sup> Ibid., p. 613

<sup>&</sup>lt;sup>51</sup> Murray & Castle 2006 (In: Gelder et al. (eds.) 2006), p. 603

<sup>&</sup>lt;sup>52</sup> Ibid., p. 601

are closely allied to psychotic experiences.<sup>53</sup> Cullberg shows the uncertainty in distinguishing misinterpretations and delusions as well as illusions and hallucinations, and a hallucination without delusion can suggest a development into psychosis if the person has been in a state of stress, states Cullberg.<sup>54</sup> Cullberg illustrates the problematic and often subtle differences between different psychotic states with six cases with six different diagnoses in the introduction of his book. This is to show the variety of diagnoses in spite of the similarities in the symptoms:<sup>55</sup>

In all these cases / presented in the book/ an intricate combination between the psychological and social circumstances and the physiological condition of the brain can be detected. 66

It is in that perspective, a bio-psycho-social-one, that Cullberg analyses and describes the concept of psychosis.<sup>57</sup> Cullberg starts his book with a quotation to pinpoint his social-interactive perspective on mental states:

Without you there is no me. 58

Cullberg states that the vulnerable personality will under different forms of stress react with psychosis.<sup>59</sup> Since Cullberg's model of psychosis includes the social perspective he also often underlines that the severity of the schizophrenic state is added to the fact that stigma and isolation as a result of being seen as "ill" makes the situation worse for the patient. <sup>60</sup>

Sometimes what appears to be 'negative symptoms' can be a side effect resulting from over-medication with antipsychotics.<sup>61</sup>

This is interesting, and pinpoints how the diagnosis of schizophrenia is stigmatizing and often devastating for the individual.

Einar Kringlen, one of Norway's most important psychiatrists, has written a textbook on psychiatry where he describes schizophrenia as a chronic disorder. He underlines that the schizophrenic disorders are a huge health problem since they are lifelong and serious

<sup>53</sup> Cullberg 2006, pp. 10-11

<sup>54</sup> Ibid., p. 41

<sup>55</sup> Ibid., pp. 12-25

<sup>&</sup>lt;sup>56</sup> Ibid., p. 25

<sup>&</sup>lt;sup>57</sup> Ibid., pp. 196-204

<sup>&</sup>lt;sup>58</sup> Ibid., p. 3

<sup>&</sup>lt;sup>59</sup> Ibid., p. 204; p. 181

<sup>60</sup> Ibid., pp. 186-188

<sup>61</sup> Ibid., p. 232

disorders that often debut at a young age and therefore last for many many years. 62 He presents a prevalence of schizophrenia in a European population of about 1%, which gives an estimation that about 10,000 people in Norway live with the diagnosis schizophrenia, half of them at inpatient clinics. 63 Kringlen discusses the so-called Langfeld perspective on schizophrenic symptoms that says that special symptoms are almost pathognomic for schizophrenia, meaning that they predict a negative prognosis and in other words confirm the diagnosis of schizophrenia. Kringlen also describes different symptomatologies with schizophrenia that can be explained by the schizophrenic person's premorbid personality, like shyness and less interest in social contact that could lead to isolation and a social degeneration.<sup>64</sup> This could mean that in the future people with schizophrenia as a group could be divided into several subgroups of different disorders. But Kringlen emphasizes that more recent research modifies that picture and there is a great similarity between "real" and "schizophreniform" psychosis.65 Kringlen also underlines how great the social influences are on the prognosis and disorder, the odd thing being how little this is used by practitioners, he says. 66 Kringlen continues by saying that since social factors have played a great role with regard to the course it is reasonable to believe that they also play a role in developing the psychoses.<sup>67</sup>

A further example is *Psykopp* (*Stiftelsen for Psykiatrisk Opplysning*) material with information that was available to the patients and relatives at the clinic where this study was done. This material affected the understanding of schizophrenia in the local context. The information material is more focused on causation and why some individuals get the disorder, since this is a common question among patients and relatives. It is not funded by drug companies but suggests the bio-genetic perspective in explaining the cause, course and outcome.

The cause of schizophrenia is unknown, according to *Psykopp*, but it is known that schizophrenia has a hereditary component as well as it is known that an overinvolved and extremely critical socioenvironment can trigger schizophrenia. <sup>68</sup> The text offers a wide definition including both bio-genetic and socio-psychological causes. <sup>69</sup> But the bio-genetic explanation is more positively described and it is stated that it is believed that genetic research will soon discover the genetic changes in schizophrenia and therefore be able to solve the so-called schizophrenia mystery as genetics has solved the mystery of allergies,

<sup>62</sup> Kringlen 1980, p. 304

<sup>63</sup> Ibid., p. 304

<sup>64</sup> Ibid., pp. 304-309

<sup>65</sup> Ibid., 310

<sup>66</sup> Ibid., p. 310

<sup>67</sup> Ibid. p. 310

<sup>68</sup> Psykopp 2001, p. 9

<sup>69</sup> Ibid. p. 9

diabetes, Huntington chorea and affective disorder. <sup>70</sup> It is also stated in *Psykopp* that even if some do not agree with the genetic explanations of today, there is a genetic core explanation that everyone agrees on. <sup>71</sup>

Other biological and environmental theories are mentioned in *Psykopp* and there is a review of some theories of the causation of schizophrenia. Bateson's theory of "double binding" is mentioned and criticized, for instance, as well as Theodore Lidz's theories of vague borders between family members and Ronald D. Laing's constructive theories understanding schizophrenia as being the last resort in impossible circumstances. But the conclusion drawn in the material is that even though stressors such as environmental factors can start off the disorder, there will always exist a predisposition. This is, according to *Psykopp*, also the idea of early intervention: preventive treatment targeting the predisposition.

#### THE RECEIVED VIEW OF SCHIZOPHRENIA

An important factor for this thesis is the publicly received view of schizophrenia. The fact that schizophrenia is presented as a severe chronic and disabling disease in many public fora deepens the stigma and largely determines the public's knowledge of schizophrenia. I want to present some examples of such presentations. This picture differs a lot from the picture presented in diagnostic manuals and it is important to see what version is presented to whom. This is also a version harboured by many clinicians and then the stigma is in line with this picture of schizophrenia.

Searching for "schizophrenia" on the internet using Google, the Wikipedia page appears first. In Wikipedia schizophrenia is described as follows:

Social problems, such as long-term unemployment, poverty and homelessness, are common and life expectancy is decreased; the average life expectancy of people with the disorder is 10 to 12 years less than those without, owing to increased physical health problems and a high suicide rate. <sup>73</sup>

It is obvious that the future is not very positive and neither is the prognosis. The next webpage in the search list is that of the U.S. National Institute of Mental Health (NIMH) and they introduce schizophrenia as follows:

<sup>70</sup> Psykopp 2001, p. 9

<sup>71</sup> Ibid. p. 9

<sup>&</sup>lt;sup>72</sup> Ibid., pp. 10-12

<sup>73</sup> http://en.wikipedia.org/wiki/Schizophrenia 2008-03-12

Schizophrenia is a chronic, severe, and disabling brain disorder that affects about 1.1 percent of the U.S. population age 18 and older in a given year. People with schizophrenia sometimes hear voices others don't hear, believe that others are broadcasting their thoughts to the world, or become convinced that others are plotting to harm them. These experiences can make them fearful and withdrawn and cause difficulties when they try to have relationships with others. <sup>74</sup>

Thus schizophrenia is presented as a chronic severe and disabling brain disorder. The hypothesis that schizophrenia could be a brain disease has been discussed widely in recent years. An article written by the Swedish philosopher Helge Malmgren analyses the total situation of publications and hypotheses regarding the genesis of schizophrenia, and the conclusion he draws is that the hypothesis regarding schizophrenia as a brain disease is not proven, there is not enough scientific facts to prove such a hypothesis.<sup>75</sup>

It is also stated in the NIMH page that schizophrenia is chronic and disabling. So there is very little hope – actually no hope – of recovery once you have received the diagnosis. But you can nevertheless learn that there is one positive thing for people with schizophrenia today: there are so many new antipsychotic medicines. The authors state that the cause of schizophrenia is unknown – even though they underline the brain disease hypothesis – but until further knowledge is available one must focus on the symptoms which are treatable with medicaments. The drugs recommended are the modern Seroquel and Geodon as well as the older antipsychotic drugs such as Risperdal and Haldol. <sup>76</sup> Schizophrenia is on the NIMH webpage likened to chronic diseases such as diabetes and high blood pressure:

Like diabetes or high blood pressure, schizophrenia is a chronic disorder that needs constant management. At the moment, it cannot be cured, but the rate of recurrence of psychotic episodes can be decreased significantly by staying on medication. Although responses vary from person to person, most people with schizophrenia need to take some type of medication for the rest of their lives as well as use other approaches, such as supportive therapy or rehabilitation.<sup>77</sup>

Number three of the top five webpages appearing when one searches for "schizophrenia" is <a href="www.mentalhealth.com">www.mentalhealth.com</a>, published in Canada, and schizophrenia is presented there as a disease with a neurobiological origin. Stress does not cause schizophrenia according to this webpage, even though they admit that stress can make the symptoms worse. On top

<sup>74</sup> http://en.wikipedia.org/wiki/Schizophrenia 2008-03-12

<sup>75</sup> Malmgren 2007, passim

<sup>&</sup>lt;sup>76</sup> http://www.nimh.nih.gov/health/publications/schizophrenia/how-is-schizophrenia-treated.shtml 2008-03-12

<sup>77</sup> Ibid., 2008-03-12

of the webpage it is stated and underlined that schizophrenia is a: "Medical illness. PE-RIOD." The authors states:

#### SCHIZOPHRENIA IS:

A brain disease, with concrete and specific symptoms due to physical and biochemical changes in the brain An illness that strikes young people in their prime -- age of onset is usually between 16 and 25.

Almost always treatable with medication

More common than most people think. If affects 1 in 100 people worldwide -- that's about 290,000 Canadians, including over 40,000 of our B.C. neighbours.

SCHIZOPHRENIA IS NOT:

A "split personality"

Caused by childhood trauma, bad parenting, or poverty

The result of any action or personal failure by the individual.

MedlinePlus – "trusted health information for you" – also introduces schizophrenia as a severe lifelong brain disorder. MedlinePlus suggests, like many other webpages antipsychotic drugs as well as electroconvulsive therapy as recommended treatment for schizophrenia. MedlinePlus has in addition a link to Consumer Reports Health, a webpage for consumers of health interventions, and they have listed the best antipsychotic drugs for schizophrenia treatment, whilst nothing is said about alternatives to drugs.<sup>79</sup>

In Sweden the information given in *Vårdguiden*, an official guide to care, is that schizophrenia is a disease<sup>80</sup> but the information is more liberal when it comes to combining drugs and psychosocial interventions such as psychological treatment.

A further example of the top ten webpages of the "schizophrenia" search on Google is Psychiatry24-7.com, a webpage sponsored by the drug company Jansen-Cilag. They describe schizophrenia as an illness of the brain that scientists believe is caused by abnormalities in the transfer and processing of information in the brain:

Nerve cells in the brain communicate with each other by releasing chemicals from their nerve endings. These chemicals are called neurotransmitters. 81

And the recommended treatment is antipsychotic drugs. They also underline the need of family support but with the further explanation:

Family and caregivers play a very important role in supporting the patient to take the medication punctually. By sticking to the medication, the patient can improve to such a degree that s/he can participate in life again.

<sup>&</sup>lt;sup>78</sup> http://www.mentalhealth.com/book/p40-sc02.html 2008-03-12

<sup>79</sup> http://www.consumerreports.org/health/best-buy-drugs-articles/antipsychotics.htm 2008-03-12

<sup>80</sup> The Swedish term is sjukdom.

<sup>81</sup> http://www.consumerreports.org/health/best-buy-drugs-articles/antipsychotics.htm 2008-03-12

Often schizophrenia patients forget or intentionally stop taking their medication when they feel better or when they experience unpleasant side-effects.

Taking a pause in the treatment can make the schizophrenia symptoms come back. Relapses are to be avoided, as they may have a permanent negative effect on the brain.82

Thus the important role of the family members is to make sure that the patients are taking the prescribed medicines, punctually, and it is only by sticking to the prescribed medicines that the patients can participate in life. Relapses are said to cause negative and permanent effects on the brain. Relapses are a risk in the case of stopping, or even taking a pause in, the medical treatments.

Much information given in the public about schizophrenia is influenced by the pharmaceutical industry. Pharmaceutical companies have a tendency to define schizophrenia as a bio-genetic disease and thus treatable with pharmaceutical compounds. Of the top 50 "schizophrenia" websites in Google and Yahoo a majority received funding from drug companies. The drug-company-funded websites were significantly more likely to present bio-genetic rather than psycho-social causal explanations. Drug-companies also emphasize medication and describe schizophrenia as an incapacitating, devastating and long-term illness which often leads to lifelong treatment. It is an obvious ethical dilemma that many drug companies influence and control research, psychiatric conferences, teaching material, information, daily work at psychiatric clinics.

# SCHIZOPHRENIA AS A DISEASE CAUSED BY BIO-GENETIC FACTORS

In the bio-genetic model emerge three main causal theories: genetic predisposition, dysfunction in the brain, and prenatal trauma (viruses or trauma, such as irreversible injuries sustained during birth).<sup>84</sup> There exists further the hypothesis of a specific protein, a "prion", in the brain that could cause schizophrenia, and this protein disease could occur through inherited genes, via contamination or spontaneously.<sup>85</sup>

During the last ten years some biological and genetic psychiatric studies have shown a heredity factor in schizophrenia. 86 Twin studies show up to 45% heredity. A close relation of a person diagnosed as having schizophrenia has a ten times greater risk of getting the diagnosis of schizophrenia as compared to the whole population. Twin studies show a concordance of the diagnosis of schizophrenia in monozygotic twins that is greater than

<sup>82</sup> http://www.psychiatry24x7.com/homes/schizophrenia.jhtml 2008-03-12

<sup>83</sup> Mosher, Gosden, Beder 2004, (In: Read: Models of Madness, 2004), pp. 115-131

<sup>84</sup> For example: Wetterberg 2000; Wetterberg et al. 2002; Maher 2003; Kemppainen et al. 2001; Morgan et al. 2001; Kendler et al. 2000; Maier et al. 2000

<sup>85</sup> Wetterberg et al. 2002

<sup>86</sup> Most of their research is based on DSM-IV definitions of diagnosis.

with dizygotic twins: the concordance is about 50 % in monozygotic twins as compared to about 5% in dizygotic twins.<sup>87</sup> This means that it is likely that 50% of those diagnosed with schizophrenia have a genetic heredity for developing schizophrenia according to these studies. Some factors are known about heredity and biological causes in schizophrenia but nothing is by itself enough as a complete explanation.

These definitions lead to schizophrenia as being regarded as a long-term biological disease, and since the genetic disposition has not been found the dysfunction is, given the current state of biotechnology, incurable. Today a dysfunction is a chronic state in the brain and oxygen loss during birth most often causes irreversible damage. This again leads to the interpretation of schizophrenia as a lifelong, mostly incurable condition that must be treated throughout the entire lifespan and often with strong medicines. This further leads to the assumption that neither the patient nor the family has any responsibility for the disease or any part of the condition. Patients diagnosed as being psychotic or schizophrenic according to this definition are then less likely to be asked about childhood trauma and of course less likely to be referred for trauma-focused treatment. 88

To some extent this is a good thing since many families earlier were blamed and extremely hurt by feelings of guilt. But it can also lead to the situation that even if it is known that the patient has had a trauma, this will have no relevance for the interpretation of the illness. This then suggests schizophrenia and life in general have nothing in common, as being two parallel processes isolated from each other.

#### SCHIZOPHRENIA AS A BIOLOGICAL CONDITION CAUSED BY TRAUMA

There are in addition studies showing that experiencing many and severe physical and psychological traumas in general and especially during childhood creates biological changes in the brain that later cause symptoms looking like for example schizophrenia. An example of such studies is Louis Cozolino's book *The Neuroscience of Psychotherapy* that shows how the brain interacts and changes as a result of such interaction, of which experiences from psychotherapy as well as abuse are examples.<sup>89</sup> An article emphasising the necessity of including history of abuse in the treatment and understanding of schizophrenia was published in 2001 by John Read, Bruce Perry and colleagues: "The Contribution of Early Traumatic Events to Schizophrenia in Some Patients: A Traumagenic Neurodevelopmental Model". There are different opinions as to whether the changes in the

<sup>87</sup> Onstad et al. 1991, p. 395; Torgersen et al. 200, pp. 33-38; DSM-IV 1994, p. 283

<sup>88</sup> Read & Goodman et al. 2004, chapter 10

<sup>89</sup> Cozolino 2002

<sup>90</sup> Read & Perry et al. 2001; pp. 319-345

brain come prior to or after an external experience, but there are very few studies of the biological and psychological changes in humans having the diagnosis of schizophrenia and being medically untreated.

# CONCLUSION

As shown in the above section, there are disparate definitions of schizophrenia regarding cause, course and outcome. The definitions vary from regarding schizophrenia as being a genetically caused biological, incurable disease needing lifelong medical treatment often in clinics — to schizophrenia regarded as an illness without any expressed causal hypotheses. One can only speculate as to how many different kinds of patients will fit into the variety of interpretations. It is then of course crucial for the further discussion which definition is used.

John Read and colleagues, as well as Kirk and Kutchins, as examples, have made studies of what effect presenting schizophrenia as a disease has on the public. <sup>91</sup> It has also been debated whether strictly medical models, involving for example defining schizophrenia as a disease, make the stigma effects worse. <sup>92</sup> Even though there is an opinion that psychosocial factors do play a role in schizophrenia, that opinion is rarely presented as important. So in exploring the different definitions I have wanted to stress the variety of interpretations and underline the received view of schizophrenia, since this is important for my further analysis and discussion.

# PRODROME THEORY

# THE PRODROME TERMINOLOGY

The aim of this study has been to look at the earliest phenomena in the process that psychiatry defines as psychotic. Theories about this phase have been developed and researched worldwide and research on the schizophrenia prodrome has become the cutting edge in psychiatric research. It is, though, important to note that psychodynamic or psychoanalytic researchers and theorists do not generally use the terminology of prodromes.

<sup>91</sup> See for example Kirk & Kutchins 1992; Kirk & Kutchins 1997; Hacking 2000; Read, Mosher & Bentall 2004; not to mention Michel Foucault 1972; Foucault 1973; Foucault 1975

<sup>92</sup> Ibid.

The prodrome terminology is instead more frequently used by psychiatrists with reference to the beginning of a pathological and to some extent biological, process. If these phenomena can be used as risk markers or warning signs for a coming psychosis there is a possibility from a psychiatric point of view of treating the condition and possibly ending a negative process. As will be shown later in the theoretical chapter, there are several different theories with regard to prodromes of psychosis, and I will in this chapter show the complexity of the terminology used today.

In theory and by definition these phenomena occur prior to a diagnosed psychotic episode. The problem is to identify when to be sure they are signs of a coming process towards a psychosis and when they are phenomena of other kinds. There is of course an overlap in reality between different stages of different processes and between different kinds of phenomena. Theoretically I have chosen to consider each of these different phenomena as an entity that occurs prior to a diagnosed psychotic condition, and do not include obvious psychotic symptoms. Again this does not mean that these phenomena stop occurring if a patient suffers a psychotic episode in reality, but the separation is made for the theoretical analysis.<sup>93</sup> I use the term "phenomena" to include both subjective and objectively observable changes and phenomena.

The term "prodrome" comes via French and Latin from the Greek "pro" and "dromos", a foreboding.<sup>94</sup>

In Roget's Thesaurus of English Words & Phrases the term prodromal is found together with the other adjectives "preceding", "foregoing", "prior", "forewarning" and "preliminary".<sup>95</sup>

In English the term "prodrome" was first used in a medical context 1861 when Bumstead identified "prodromes" of venereal diseases. "Prodrome" was used in an English medical dictionary for the first time in 1864 in Thomas's *Medical Dictionary*, where vertigo is described as a presentiment of apoplexy.<sup>96</sup>

The Swedish *Nationalencyklopedin* describes the "prodromal stadium" in connection with somatic diseases and conditions such as epilepsy and migraine. The descriptive definition is according to *Nationalencyklopedin*:

Prodromer (Lat. prodromus) "foreboder", "courier" 97

# Psykologilexikon defines "prodromal symptom" as follows:

<sup>93</sup> See further discussion in Chapter 3: "Fundamental concepts introduced".

<sup>94</sup> Nationalencyklopedin 1994, volym 15, p. 288, (AKN translation).

<sup>95</sup> Kirkpatrick 2000, p. 28

<sup>&</sup>lt;sup>96</sup> The Compact Oxford English Dictionary 1993, p. 563

<sup>97</sup> Nationalencyklopedin, 1994, p. 288, (AKN translation).

Presymptoms. Symptoms that give a hint of a certain disease, for example agony and confusion before developing postoperative confusion. <sup>98</sup>

# And the prodromal phase as:

During the period when "prodromal symptoms" occur 99

Different researchers and theories use different terminology for these phenomena. In Sweden the terms *prodromaltecken* and *prodromalsymtom* are used, corresponding to the English "prodromal sign" and "prodromal symptom". The specific "prodromal phase" is also described as a more all-embracing condition including several prodromal phenomena. The theoretical field is new and the terminological abundance may not reflect a real abundance of phenomena. The terminology also causes ambiguity. A "prodromal sign" defines something observable, while a "prodromal phenomenon" also can include a more inner and subjective experience. The term "prodromal symptom" involves a relation to a disease and the symptom is then already part of a pathological process. Problems do occur when these terms are used as synonyms in a psychiatric practice.

In the Diagnostic and Statistical Manual of Mental Disorders (DSM III and DSM-IV) the term "prodromal *phase*" is used, and it includes "prodromal *signs*" and "*symptoms*". Here the phenomena are seen as early signs of an already started process. "The majority of individuals display some type of prodromal phase manifested by the slow and gradual development of a variety of signs and symptoms." These prodromal symptoms are not by themselves enough for diagnosis according to DSM-IV. There are also research groups that consider these phenomena representing a "prodromal phase" with specific "prodromes" as risk markers of a psychotic condition, but so far not yet a started process. EPPIC in Australia is an example of such an interpretation. They also have an interpretation like the definition in DSM indicating that prodromes could be the earliest phenomena in a pathological process. EPPIC's terminology and theory will be analysed in Chapter 2. Johan Cullberg uses the following terminology in his *Psychosis*:

This phase, which particularly characterises those psychoses we term schizophrenic, can only be identified with certainty if followed by a psychotic episode.  $^{103}$ 

<sup>98</sup> Egidius 1997, p. 430, (AKN translation).

<sup>99</sup> Ibid., p. 430, (AKN translation).

<sup>100</sup> DSM-IV 1994, p. 282

<sup>101</sup> Ibid., p. 282

<sup>102</sup> Edwards & McGorry 2002, p. 25

<sup>103</sup> Cullberg 2006, p. 50

He describes a phase which is hard if not impossible to define and separate from other psychological crises or disorders.

We certainly do not know either how we should differentiate prodromal symptoms from other psychic crises or disorders. As yet, no one has been able to give a valid diagnostic description of the differences. <sup>104</sup>

Cullberg uses the term "symptoms" as if these phenomena can be defined and separated as part of a current process. He uses a retrospective definition since he does not believe in identification in the active phase. He believes, on the basis of current knowledge of the phase, that it is only after a diagnosed psychotic episode that it is possible to say that prodromes have been present prior to the psychosis. In the quotation above prodromal symptoms of schizophrenia are described.

Other researchers, such as Paul Møller, to whom I will return, use the terms "prodromes" and "prodromal features". He describes in his thesis that there are two different kinds of prodromes, one group that are more likely to be foreboding a coming psychosis, and another group that have a weaker relation to a coming psychotic process. Møller states:

 $\dots$  certain mental phenomena appear to be more intrinsic to core psychosis phenomenology  $\dots$  whereas others are probably less intrinsic  $\dots$  rather accompanying features.  $^{105}$ 

Some definitions, according to Møller's terminology, can therefore be considered as denotive core dimensions of a psychosis – and therefore denote part of the psychosis. Møller asks why these phenomena have to be so severe (psychotic) before they can be treated, which leads to the conclusion that treatment could start as early as during the active prodromal phase.

Another dimension of the problem is how the terminology is used in psychiatric practice. Recently several researchers have emphasized the need of early intervention in severe mental conditions to get a positive prognosis. <sup>107</sup> The possibility is that these phenomena are used as markers to start treatment for a psychotic, especially schizophrenic condition.

Prodromes discussed in this study are phenomena *prior to* the first diagnosed psychotic episode. This is only a time specification – whether the phenomena are part of the psychosis by definition or not will be discussed later. There is also a possibility of defining

<sup>104</sup> Cullberg, 2006, p. 50

<sup>105</sup> Møller 2001, pp. 8-14

<sup>106</sup> Ibid., pp. 8-14

<sup>107</sup> See Chapter 3: "Prodrome Theory"

phenomena prior to a recurrent psychosis but that possibility is not followed up in this study. Since there is little and only scattered knowledge about prodromes of first-episode psychosis and even less about the prevalence of prodromes of recurrent psychosis, I have deliberately excluded the difference from this theoretical study. In reality it is today almost impossible to strictly determine the exact time for the psychotic outburst and whether – if so, at what intensity – prodromal, prepsychotic or psychotic symptoms have occurred.

One prospective concept that has been suggested and studied, is that of the "ultra high risk group" (UHR) or "at-risk mental state" (ARMS), used for example at the PACE clinic 108 and mentioned in the theory chapter of this thesis. There are many leading institutes – the PACE clinic being one - that, instead of defining prodromes, are trying to define high-risk groups of patients, meaning instead of being in the initial or the prodromal phase of a psychotic disorder you have an increased risk of progression into a psychotic disorder. Other suggested terms are "clinical high-risk" (CHR) and "schizophrenia-likepsychosis" (SLP), used in Hillside Recognition and Prevention in New York (Hillside-RAP). 109 Concerning "ultra high risk" and "at-risk mental state" the term stands for "the presence of the syndrome [that] implies that the affected person is at that time more likely to develop psychosis in the near future than someone without the syndrome." Also this concept can be debated since, as mentioned above, the transition rates are as low as 30% so even if you are in this UHR group there is still only a rather small risk of progression. Another difficulty is the term "near future" - for how long does the presence of the syndrome confer a heightened risk on an individual? And for how long after should the person be considered at high risk?<sup>111</sup> Does the individual return to having no increased risk immediately after the disappearance of the syndrome, or does the fact that the person has been in the UHR group mean that she remains at risk for some time after?<sup>112</sup> All these, and other questions, are discussed by Alison Yung in an article published in Early Intervention in Psychiatry in 2007.

There is another difficulty with the concept "Ultra High Risk" (UHR): "That is, they are considered to be potentially in a state of incipient psychotic disorder or possibly "prodromal" "Alison Yung says in the article mentioned above. 113 There is a weakening of the "prodromal" definition into "possible prodromal", and the patients are considered to be "potentially" at high risk of progression, which must be considered quite a weak terminology. A further thing is that many of these patients discussed in the review article con-

<sup>108</sup> Yung 2007, pp. 226-227

<sup>109</sup> Ibid., p. 227

<sup>110</sup> Ibid., p. 227

<sup>111</sup> Ibid., pp. 225-226

<sup>112</sup> Ibid., pp. 225-226

<sup>&</sup>lt;sup>113</sup> Ibid., p. 226

cerning the PACE Clinic work and considered as ARMS or UHR were referred to the clinic from nonspecialized services that considered the patients as having a first episode of psychosis. This means that the patients were considered psychotic by nonspecialized health-care personnel and after being examined at the very specialized clinic were instead considered at high or ultra-high risk of psychotic disorder. This indicates an additional difficulty in defining these phenomena which is interesting. The discussion has been the possibility of identifying persons at risk of a psychosis, the suggestion being that this should be done by different kinds of health-care personnel, for example school psychologists, or unspecialized psychiatrists. To be able to use preventive psychiatry in the case of a large population the knowledge must be handled by many and diverse health-care personnel. Since the phenomena are both nonspecific and vague the risk in using them in preventive circumstances increases. Alison Yung points out that today the UHR criterion is not recommended for use in a general community.<sup>114</sup> This problem must also be seen in the light of the difficulty of defining and identifying other constructs related to the definition of "prodromes" - such as first-episode psychosis (FEP), duration of untreated psychosis (DUP), early symptoms in schizophrenia, different psychotic disorders, affective disorder and personality disorders. 115

Also German psychiatry has redefined the "prodromal phase" of psychoses. The Cologne Early Recognition Study has delineated two different stages as "early initial prodromal state" (EIPS) and "late initial prodromal state" (LIPS). He both are parts of an initial prodromal state but more symptoms occur in the late initial phase. It was also in Germany that the first intervention centre was established in 1997. This was at the Department of Psychiatry at the University of Cologne, the *Früh-Erkennungs & Therapie-Zentrum* (FETZ). At this centre the EIPS patients were offered psychotherapy and the patients considered as having LIPS were offered pharmacotherapy. He

There are of course more concepts and terminology that could have been explored but this chapter has only been designed to display the terminological complexity in the field. The complexity is on three levels of understanding, the lexical, the terminological and the diagnostic; more about the theoretical complexity in the following.

<sup>114</sup> Yung 2007, pp. 226-227

 $<sup>^{115}</sup>$  This problem is discussed in many papers, for example these recent studies: Compton et al. 2007; Nelson & Yung  $^{2007}$ 

<sup>116</sup> Yung 2007, p. 228

<sup>117</sup> Ibid., p. 228

# OVERVIEW OF EMPIRICAL RESEARCH ON THE SCHIZOPHRENIA PRODROME

Traditionally to designate a phase as prodromal to psychosis there has been needed a diagnosed psychotic episode. No prodromal signs or symptoms are listed in DSM or ICD as diagnostic criteria, still many researchers have published studies that analyses the phase in depth, and the prodromal phase is mentioned in the diagnostic manuals. These concepts and their implications will be thoroughly analysed later in this Part.

Nevertheless it is necessary to mention that there are several lists and definitions of prodromes of psychosis that are used in practice, many more than those analysed in this thesis. One of the most widely spread lists is the TIPS (*Tidlig Intervensjon ved Psykotiske Symptom*) list, developed and used in a Nordic context. This is a checklist of prodromes of schizophrenia distributed and used by doctors and health-care personnel in Norway for example. The TIPS list is a result of cooperation between Norway, Denmark and Sweden and the purpose is to increase the knowledge about psychosis and lessen the duration of untreated psychosis. The list is based on the DSM criteria and developed by Einar Kringlen and Tor Ketil Larsen among many others. TIPS makes use of both DSM and the IEPA (International Early Psychosis Association) list as a base. The symptoms do agree to some extent with the phenomena presented by Paul Møller and more thoroughly analysed in this thesis. One difference between the TIPS list and Paul Møller's list is that Møller's is more subjectively oriented, especially with regard to his core dimensions.

There are many different articles on prodromal phenomena published, most of them by quantitative method screening and identifying changes prior to a psychotic episode. One of the first inventories published of prodromal phenomena was the *Bonn Scale for the Assessment of Basic Symptoms* (BSABS). Later the PACE clinic in Australia published the *Comprehensive Assessment of At-Risk Mental States* (CAARMS). Structured Interviews for Prodromal Symptoms (SIPS) and the *Scale of Prodromal Symptoms* (SOPS) are developed from CAARMS while *Criteria of Prodromal States* (COPS) is more a newly developed inventory from the work at the PACE clinic.<sup>118</sup>

However, the number of articles published employing qualitative method and attempting to identify the phenomenology of the prodromes was up until 2001 still marginal. Ethical issues with interventions and detection in the prodromal phase, as well as conceptual discussions were analysed in several psychiatric publications. A general conclusion was that early interventions in psychosis are difficult but important for psychiatric health

<sup>118</sup> Amminger et al. 2005, passim

services.<sup>119</sup> Interventions aiming at reducing DUP have been considered to be the most promising strategy according to Tor Ketil Larsen just to give an example.<sup>120</sup>

The definitions and texts used in this thesis are not today enough for diagnosing. There has also been a great discussion about the non-specificity of the prodromal lists and in Australia they are now working with complementary entities called BLIP (Brief Limited Intermittent Psychotic episode), see the section on PACE and EPPIC below. A BLIP episode is considered to be a condition for a person being said to be in an early psychotic phase. All these inventory lists and theories about the prodromal phase of psychosis and schizophrenia are vast and the development is fast.

Paul Møller has developed his thesis into a symptom checklist called EASE (Examination of Anomalous Self-Experiences). Møller has with Josef Parnas, Dan Zahavi and others developed a "checklist for semi-structured, phenomenological exploration of experimental and subjective anomalies that may be considered as disorders of basic or "minimal self-awareness". <sup>121</sup> This checklist focuses on disorders of self-awareness and the design is for conditions in the schizophrenia spectrum. <sup>122</sup> In designing the checklist the aim was to detect disorders of the self and the approach is phenomenological and existentialistic. Still this EASE checklist is not a diagnostic instrument for diagnosis in the schizophrenia spectrum but it is an instrument for the detection of anomalies that often occur in the prodromal phase of schizophrenia, as the authors say. <sup>123</sup>

Methodologically different prodromal assessment instruments are used in these studies, for example BSABS, PACE and CAARMS.<sup>124</sup> Haroun and others grant the potential for early intervention and possible prevention of the illness but they stress the limits of the current data. They also point out the non-specificity of the rating scales and they close with the statement that clinicians need to be able to rely on an assessment that includes facts about the intricacies of different diagnoses.<sup>125</sup>

To demarcate this thesis I have chosen some theories for a more detailed analysis, and these theories are used as examples of prodrome research. The theories have been chosen since they are well-known and often referred to. They were also well-known at the clinic where the interviews were performed. I of course wanted to analyse theories as well-known as possible to the therapists at the clinic, since they were the ones to define which patient was in a possible prodromal phase and who was not. The theories were physically available at the clinic where this study was performed, both to me and to all the therapists

<sup>119</sup> See for example: Larsen et al. 2001; McGlashan 2001; McGorry et al. 2001; Haroun et al. 2006; Yung 2007

<sup>120</sup> Larsen et al. 2001; Larsen et al. 1998

<sup>121</sup> See for example: Parnas, et al. 2005

<sup>122</sup> Ibid., p. 236

<sup>123</sup> Ibid., p. 237

<sup>124</sup> Haroun, et al. 2006

<sup>125</sup> Ibid., p. 166; 174-176

working there. Cullberg's theories and books are well-known internationally and often used in psychiatric learning and practice. I also knew that his theories were used by many therapists at the clinic, and in current further education at the clinic. The EPPIC clinic with Paul Amminger, Jane Edwards and Patrick McGorry was maybe the easiest choice since it is considered almost all over the world to be the leading clinic in early psychosis research. To choose Paul Møller was also easy since he was an important actor in the field of prodromes of schizophrenia at the time of this study's start, both for Norwegian and for international researchers and practitioners. He was the first psychiatrist in Norway to use a qualitative research method and the first to identify the subjective dimension of the initial phase of psychosis. He had also visited the clinic in focus for this study several times to lecture about his theories. At the clinic the diagnostic manual ICD-10 was used in daily practice, so this manual is used in the chapter of definitions. I have also used DSM-IV since that manual is a well-known world-wide and more frequently used in research. The empirical part of my thesis was done in Norway, and it was natural to choose Møller's writing to illustrate different interpretations of the schizophrenia prodrome theories.

# The texts chosen are:

- Johan Cullberg's *Psychoses*.
- Jane Edwards and Patrick McGorry's *Implementing Early Intervention in Psychosis: A Guide to Establishing Early Psychosis Services*, especially Chapter "Prodromal phase" 126 and Paul Amminger, Steven Leicester, Shona Francey, and Patrick McGorry's "The Prodromal Course" in: *Juvenile-Onset Schizophrenia*.
- Paul Møller's The Phenomenology of the Initial Prodrome and Untreated Psychosis in First-Episode Schizophrenia. An Exploratory Naturalistic Case Study.<sup>127</sup>

I have further allowed myself to apply Jane Edwards and Patrick McGorry's as well as Paul Møller's list on the material.

# JOHAN CULLBERG'S DEFINITION OF PRODROMES

Johan Cullberg, professor of psychiatry and specialist in psychosis, has written several books on psychiatry, *Dynamisk Psykiatri* and *Psychoses* just to mention two.<sup>128</sup> His definitions of psychoses are based on both psychiatric and phenomenological theories. Cull-

<sup>126</sup> Edwards & McGorry 2002

<sup>127</sup> Cullberg 2006; Edwards & McGorry 2002; Amminger et al. 2005; Møller 2000

<sup>128</sup> Cullberg, 1984; Cullberg, 2006

berg says that since every attempt to find a neurobiological marker for different psychiatric conditions – for example psychoses – has failed, he instead argues for the need of a phenomenological understanding in psychiatry. 129

The prodromal phase of psychosis is by definition retrospective according to Cullberg. It is not, in his theory, certain until after a diagnosed psychotic episode that a phenomenon or phase can be defined as prodromal. But in retrospect it is often obvious that a phase has occurred prior to a psychotic episode. Different perceptual changes can occur, like heightened experience of light, colour or sound, and a tendency to react strongly to different kind of stimuli is often reported, says Cullberg and the phase can be likened to:

...an irreconcilable guilty feeling that one has committed a terrible crime that no one else knows of ... The prodromal phase contains diffuse feelings of approaching breakdown in the ability to understand and to deal with reality.<sup>132</sup>

In *Psychoses* there is no mention of the possibility of an actual cause and effect relation between the prodromal changes and trauma. But severe trauma or lack of care affects people negatively, and these circumstances can lead to severe psychiatric conditions. <sup>133</sup> It is not likely that negative childhood experiences could cause schizophrenia according to Cullberg, thus in his own research he found that patients who had recovered from schizophrenia often had stressful experiences during later development, preschool age or preadolescence. <sup>134</sup>

Even though Cullberg is not proclaiming a prospective definition of prodromes of psychosis he suggests a shortening of the prodromal phase for the benefit of a positive prognosis.

The period preceding psychiatric treatment must be made as short as possible in order to diminish the psychological and social damage caused by the psychosis, that is to say, the time from the inception of the prodromal symptoms.<sup>135</sup>

Meaning that treatment is in the future probably possible and even recommended as early as in the prodromal phase. It is not defined what kind of treatment but he refers to recent

<sup>&</sup>lt;sup>129</sup> Cullberg 2006, p. 51 – As mentioned before this does not apply to the organic or substance-induced psychosis, where the cause is clearer.

<sup>130</sup> Ibid., pp. 50-51

<sup>131</sup> Ibid., p. 141

<sup>132</sup> Ibid., p. 141

<sup>&</sup>lt;sup>133</sup> Ibid., pp. 73-87

<sup>134</sup> Ibid., pp. 73-87

<sup>135</sup> Ibid., p. 158

studies that suggest there is a possible toxic neurodegenerative effect on the brain during untreated psychosis. <sup>136</sup> Cullberg thus underlines that there is not enough scientific evidence for the hypothesis – the hypothesis could be a result of many clinicians opinion that long period of untreated psychosis is related to a poorer prognosis, this attributed to the social and psychological effects of long-term isolation with severe symptoms. This hypothesis is very much debated and not scientifically proven. <sup>137</sup>

To conclude concerning Cullberg's theory on prodromes of psychosis, this phase can only be defined *after* a diagnosed psychosis. The duration of the phase can be between weeks and years. The phase is characterized by changes in experience, without the phenomena being psychotic. The phase also includes functional deprivations, which for some patients makes it hard to work or study. The *intensity* of the changes and symptoms is an indicator of the phenomena which can be called prodromal, prepsychotic or psychotic. That means low intensity for prodromes and stronger intensity for prepsychotic and psychotic experiences.

Negative childhood experiences, such as child abuse, probably increases the vulnerability for later psychotic episodes but infant abuse is not an indication for later psychosis according to Cullberg.

# PACE AND EPPIC

One of the leading clinics in the world on prodromal research is the EPPIC centre in Australia. Professor Patrick McGorry is the head of it and many of the world's most prominent researchers on the topic are working there or have been working there, such as Jane Edwards and Paul Amminger.

Researchers from these clinics have in several papers underlined the importance of early identification and interventions in psychosis:

Early intervention in psychosis aims to improve recognition and access, promote recovery from the initial psychotic episode, minimize secondary morbidity and reduce collateral damage. It may also prevent some brain dysfunctions and damage, which may otherwise occur later in the illness. <sup>138</sup>

This also indicates that they believe that untreated psychosis and untreated schizophrenia in particular are toxic conditions and generate brain damages. Many scientific papers from

<sup>136</sup> Cullberg 2006, p. 160

<sup>137</sup> Whyatt 1997; Ho et al. 2005; Norman et al. 2001; Bola 2006

<sup>138</sup> McGorry & Yung 2003, pp. 393; see also Yung et al. 2006; McGorry et al. 2002

the clinic further consider schizophrenia as arising from early abnormalities in the development of the brain.

We propose first, that early neurodevelopmental insult interacts with either normal or abnormal post pubertalbrain maturation to produce further (late neurodevelopmental) brain structural and functional changes: and secondly that the effect of such neurodevelopmental lesion will have different consequences for functions that normally develop early in life. ... a model is presented that suggest that the structural and functional abnormalities in schizophrenia can be understood as a consequence of the neurodevelopmental stages at which brain changes occur. <sup>139</sup>

Researcher Paul Amminger has written an article on the "Prodromal Course" together with Steven Leicester, Shona Francey and Patrick McGorry. Amminger and co-workers describe their interest in the field as stemming from its potential of early intervention. It article explores the prodromal phase of schizophrenia and other psychotic illnesses, considering rating scales, and explores age-specific characteristics of the prodrome and the transition to psychosis. It authors describe the prodrome as follows:

Prodrome refers to the early symptoms of an illness that precede the manifestation of the fully developed disorder or to a period of disturbances that represents a deviation from a person's previous experience and behavior. ... Prodromal symptoms such as perceptual distortions, short transient hallucinations or mild paranoia are common in schizophrenia and can be thought of as the earliest forms of emergent psychosis. <sup>143</sup>

The three terms "illness", "disorder" and "disturbance" are used in the paper to describe the psychotic condition. Since the prodromes are defined as "symptoms" one can argue that Amminger and colleagues sees them as a possible part of a started process. They later specify that "prodromes" can only be defined retrospectively and that in the actual ongoing phase the term "at risk mental state" should be used. This is since the "symptoms are far more prevalent in the general population than in clinical cases of psychotic disorders". 144

Disturbances in individuals who have not yet experienced a psychotic episode should be viewed as indicators of a risk of psychosis, rather than as signs that inevitably signal the start of a progression into a psychotic disorder. The term at-risk-mental-state has been used to describe such symptoms. The concept of an at-risk men-

<sup>139</sup> Pantelis et al. 2003, p. 399

<sup>140</sup> Amminger et al. 2005

<sup>141</sup> Ibid., p. 199

<sup>142</sup> Ibid., p. 199

<sup>&</sup>lt;sup>143</sup> Ibid., p. 200

<sup>144</sup> Ibid., p. 200

tal state can be applied prospectively, whereas a prodrome can be defined only retrospectively, once a disorder has been diagnosed. 145

This is in accordance with the definition of prodromes by Cullberg, who states that the prodrome terminology can only be used with retrospection of a psychotic disorder.

Most research on the prodrome has been done on the schizophrenic prodrome, a fact that Amminger and colleagues also emphasize, and the most detailed list of prodromal symptoms is the one made by Yung and colleagues in 1996, they say. They accentuate how difficult it is to clearly define the difference between "different but not psychotic" and "frankly psychotic", for which reason it is of course also hard to define the border between "prodromes" and "psychoses".<sup>146</sup>

Amminger and colleagues also draw attention to the fact that retrospective reconstructions have been tried by clinicians and researchers since the idea of schizophrenia was invented by Bleuler in 1911. Amminger and colleagues analyse the different research on prodromes and conclude with a "stress-vulnerability model". They do show that different biological changes could be related to transition to psychosis but these findings are so nonspecific that they need to be used with care. They also affirm that:

Developmental changes during adolescence, including neurobiological and neurocognitive changes, may contribute to an individual's vulnerability to psychosis. Environmental stressors such as relationship problems, difficulties in managing societal commitments or problems with lifestyle generally appear to increase the vulnerability. 147

This is also in accordance with the definition given by Cullberg, that trauma as well as other causal factors could increase the vulnerability for psychoses.

Within a group of individuals with either "a family history of psychotic disorder, schizotypal personality disorder, subthreshold psychotic symptoms or brief limited transient psychotic symptoms (BLIPS)" such factors as "long duration of prodromal symptoms, poor functioning and intake, low grade psychotic symptoms, depression and disorganization" were highly significant for a coming psychosis. <sup>148</sup> For this group – called the Ultra High Risk Group (UHG) – McGorry argues that rather small interventions are needed to detect a progression into a psychotic episode.

<sup>145</sup> Amminger et al. 2005, p. 200

<sup>146</sup> Ibid., p. 201

<sup>&</sup>lt;sup>147</sup> Ibid., p. 210

<sup>148</sup> Yung et al. 2003

Given the broad variety of nonspecific symptoms that occur in the prodromal phase and their relatively high prevalence in the general population an awareness of the risk of false-positives is crucial for those designing intervention strategies for individuals considered at immediate risk for psychosis.<sup>149</sup>

Thus there are some interventions that can be recommended, according to Amminger and colleagues such as easy access to care and close follow-up, which are seen as key elements of interventions in the prodromal phase.<sup>150</sup> There have been several papers published by researchers from the EPPIC on the need of treatment interventions as early as possible in the initial phase as well as the early course of schizophrenia since duration of untreated psychosis is seen as a predictor of outcome.<sup>151</sup> In published material from the PACE clinic and EPPIC centre and its researchers there is an overall interest and focus on starting interventions as early as possible, this includes pharmacotherapy.<sup>152</sup> Australian researchers have also been in the front line for community campaigns for identifying people with early signs of psychosis.<sup>153</sup>

There are ethical issues discussed by Amminger and colleagues in the article with neuroleptic treatment in the prodromal phase. One issue is transitions rates, only one third of the group with prodromal signs develop psychosis, so the majority of individuals are "exposed to potentially harmful medications for no reason. Indeed, the effects of antipsychotics on the developing brain are unknown." Despite this they give a modest recommendation for new atypical antipsychotics agents since they have fewer serious side-effects. 155

Amminger and co-workers also discusses side-effects of antipsychotic drug interventions in the prodromal phase and states that the most frequent ones were akathisia, sedation and weight gain. <sup>156</sup> Rather serious side-effects if used as long-term treatment interventions.

Amminger and co-workers conclude regarding that:

At present there is no general indication for treatments aimed specifically at reducing the risk of a progression to psychosis. Moreover, antipsychotic medications are not usually indicated unless the person meets the criteria for a DSM-IV and/or ICD-10 psychotic disorder. <sup>157</sup>

<sup>&</sup>lt;sup>149</sup> Amminger et al. 2005, p. 207

<sup>150</sup> Ibid., p. 207

<sup>151</sup> Compton et al. 2007

<sup>152</sup> See for example: Yung 2007; Nelson & Yung 2007

<sup>153</sup> This study mainly is focusing on DUP, Krstev et al. 2004

<sup>154</sup> Amminger et al. 2005, p. 208

<sup>155</sup> Ibid., p. 208f

<sup>156</sup> Ibid., p. 208

<sup>157</sup> Ibid., p. 215

The authors do list exceptions such as fast deterioration or suicide risk, when drugs could be considered.<sup>158</sup> The PACE clinic uses integrated psychotherapy and they have developed at the clinic cognitive strategies to strengthen the individual's coping resources.

A central publication from the EPPIC centre is *Implementing Early Intervention in Psychosis*, from which I have allowed myself to apply a list of prodromal signs to the interpretation of the empirical material.

In their book it is stated that a:

period of behavioural or functional changes prior to the onset of obvious psychotic symptoms is referred to as the prepsychotic prodrome. In most cases, the prodrome is defined retrospectively once a diagnosis of psychotic disorder has been made. 150

According to the text the prodrome can be considered in two ways:

- the earliest form of a psychotic disorder
- a syndrome conferring increased vulnerability to psychosis that is, an "at risk mental state", or "precursor state" (160)

The features listed in the book are (in descending order of frequency):<sup>161</sup>

- Reduced concentration, attention
- Reduced drive and motivation, anergia
- Depressed mood
- Sleep disturbance
- Anxiety
- Social withdrawal
- Suspiciousness
- Deterioration in role functioning
- Irritability<sup>162</sup>

This list largely defines observable behaviour changes and changes that relatives and others can observe. The next list presented by Paul Møller is more a list of subjective and inner changes. Many of these symptoms are also neurotic-like disturbances that appear in many different forms of mental conditions. I have used the above list in the interpretation of the empirical material with the help of professor Lisbet Palmgren as a hypothetical list

<sup>158</sup> Amminger et al. 2005, p. 215

<sup>159</sup> Edwards & McGorry 2002, p. 25

<sup>160</sup> Ibid., p. 25

<sup>&</sup>lt;sup>161</sup> Ibid., p. 25

<sup>162</sup> Ibid., p. 25

of diagnostic entities. The list is based on several lists published and researched on and according to Edwards and McGorry these are the most commonly described prodromes in first-episode psychosis.<sup>163</sup> It is important that Edwards and McGorry always define first-episode psychosis and not necessarily first episode schizophrenia.

Since the prodromal symptoms are so unspecific, Edwards and McGorry suggest that interventions should be limited. However, the authors do believe in increased attention to the "at risk group" of individuals.<sup>164</sup>

A survey done by McGorry and his colleagues in Australia showed that many young people had negative views regarding the helpfulness of recommended pharmacological treatment, and their conclusion was that there is a need for an initiative to enhance mental health literacy among young people.<sup>165</sup>

To conclude, EPPIC and PACE underline that several psychotic illnesses are preceded by prodromal changes – but research has merely focused on the schizophrenia prodrome. They believe in the necessity of early detection and intervention, and the focus of the research has been on finding markers for early identification and interventions: the prodromal phase being one focus.

Researchers from EPPIC and PACE stress that the prodromes are unspecific and introduce another complementary definition of "at risk mental state" for the individuals that have not yet suffered a psychotic episode.

# PAUL MØLLER'S THESIS ON THE PRODROMES OF SCHIZOPHRENIA

The Norwegian doctor of psychiatry Paul Møller has, with the professor of psychiatry Ragnhild Husby, analysed and studied the prodromes of schizophrenia. Their study is explorative and focuses on patients' early subjective experiences in their first episode of psychosis (First Episode Psychosis – FEP). Their research is among other places published in Møller's thesis *The Phenomenology of the Initial Prodrome and Untreated Psychosis in First Episode Schizophrenia*, as well as in *Schizophrenia Bulletin* and in *Psychophatology*. <sup>166</sup>

The main aim of Møller and Husby's research is to identify and analyse the initial changes in the early and prepsychotic phase of a process towards schizophrenia. Their research is what they call naturalistic, which by their definition involves an approach as open-minded as possible. Nineteen patients and relatives were interviewed. The very early

<sup>163</sup> Edwards & McGorry 2002, p. 25

<sup>164</sup> Ibid., p. 27

<sup>165</sup> Wright et al. 2005 pp. 18-23

<sup>166</sup> Møller 2000; Møller & Husby 2000, Møller 2001

phenomena found and described in the interviews are listed and defined. Møller argues that these phenomena that he calls "prodromes" or "prodromal features" can be seen as markers for a coming psychosis. One aim of the research was to answer the following question:

Which prodromal changes in subjective experiences are reported by first episode DSM-IV schizophrenic patients;<sup>167</sup>

# They continue:

We must understand better what we are going to detect, because the essential parts of this phase, the subjective experiences, remain unsettled. 168

The aim is to identify subjective experiences and how they are reported, as well as "which prodromal changes in *behaviour* are reported by their families and friends (or even by the patients themselves)."<sup>169</sup>

Interestingly, Møller is the first psychiatrist in Norway to do his thesis with a qualitative method and he is also one of few that focused on philosophical issues of psychiatry. He underlines the need of qualitative studies to explore the phenomenology of the phenomena:

What promotes or restrains the subject's perception, interpretation and communication of these experiences?<sup>170</sup>

Møller is looking for subjective changes, not merely observable changes. Two main issues are analysed in his thesis:

- 1. Psychosis onset
- 2. Subjective experiences. 171

Møller identifies two different groups of prodromes – one that more likely will develop into a psychotic state and one that has a weaker relation to a coming psychosis.

<sup>167</sup> Møller & Husby 2000 p. 218

<sup>168</sup> Ibid., p. 217

<sup>169</sup> Ibid., p. 217f

<sup>170</sup> Ibid., p. 218

<sup>171</sup> Møller 2000 p. 8-12

...certain mental phenomena appear to be more intrinsic to core psychosis phenomenology ... whereas others are probably less intrinsic ... rather accompanying features. <sup>172</sup>

Some features are part of core psychosis phenomenology and that is seen as part of the psychosis, then pathological, and of special interest for interventions according to Møller. Møller also discusses if it is necessary to wait for the phenomena to develop into psychosis before interventions can be made.<sup>173</sup>

As to medication: why should a symptom reach a certain level of severity (psychosis) before treatment is indicated? 174

Møller & Husby list the phenomena that occur often or are spoken about often, in order of appearance; all phenomena that occur with "striking predominance" are listed. The core dimensions of subjective prodromal features defined are:<sup>175</sup>

- Disturbance of perception of self (16).
- Extreme preoccupation with and withdrawal to overvalued ideas (14).
- Neurotic-like disturbances (14).
- Disturbance of formal thought (13).
- Attenuated delusional ideas or perceptions (13).
- Disturbance of mental/inner control (8).
- Secondary coping/relieving responses (7).
- Disturbance of simple perception (6).

This list is the other list I have applied on the empirical material.

These dimensions will be used in the prodromal interpretation of the interviews done for this thesis, and are then naturally further explained.

One central theme for Møller is *change*. If a family member seeks help from psychiatry because something has *changed* sometimes without the possibility of defining the change, then this is a risk factor for Møller.<sup>176</sup> Møller was a psychiatrist at the clinic where the research was conducted. The patients were originally diagnosed by some other psychiatrist and referred to Møller's clinic and he describes how he was interested in information from other parties like relatives.<sup>177</sup> After the acute psychotic phase the patients and the relatives were interviewed by Møller as part of the treatment:

<sup>172</sup> Møller 2001, p. 11

<sup>173</sup> Ibid., p. 11

<sup>174</sup> Ibid., p. 11

<sup>&</sup>lt;sup>175</sup> Møller & Husby 2000 p. 222 Numbers refers to reported occurrence, total number of patients were 17.

<sup>176</sup> Møller 2000 passim

<sup>&</sup>lt;sup>177</sup> Møller & Husby 2000, p. 219

*In fact, we saw these in-depth elaborations as parts of treatment* .... <sup>178</sup>

Møller discusses the First-Episode Psychosis, focusing on schizophrenia. He describes the four stages in the process as the prodromal phase, the prepsychotic phase, the psychotic phase and schizophrenia. Obviously this process also can restart with relapses. But as said in the introduction, his theoretical analysis is only of first-episode psychosis.

Møller discusses in his thesis that there has been shown to be objectively measurable biological changes in the brain of the psychotic patient and he thinks there is more deprivation of the functions in the brain for every psychotic episode the patient experiences. This leads, according to Møller, to a lessened ability for rehabilitation and a decrease of the treatment potential with every new psychotic episode. Møller also believes in a correlation between DUP (Duration of Untreated Psychosis) and response to treatment, both with short- and long-term responses. He believes in the hypothesis that there could be an ongoing toxic process during an active psychotic process that damages the cells in the brain irreversibly.<sup>179</sup> The main thing is to lessen the damage the psychotic condition leaves in the brain – hence the importance of early identification of phenomena in the process towards schizophrenia.

The main ambition with early intervention, according to Møller, is to lessen DUP and by that improve the potential prognosis. <sup>180</sup> Another ambition, related to Møller's own research, is to be able to start interventions before severe symptoms have appeared. <sup>181</sup> That means *in the active prodromal phase* and by definition a prophylactic intervention. To be able to identify the active prodromal phase Møller has identified a list of prodromes and an interview guide called EASE (Examination of Anomalous Self-Experiences). <sup>182</sup>

To conclude concerning Møller's theories about the prodromes: Møller believes that negative childhood experiences can contribute to an already existing genetic vulnerability. He is convinced that DUP does have an effect on prognosis. He also believes that the longer patients are untreated the greater the risk of negative effect on the brain. He believes there is a continuing toxic process during DUP. Because of this Møller is eager to find markers – prodromes – to identify an active prodromal phase to start interventions even prior to a diagnosed psychotic episode.

<sup>&</sup>lt;sup>178</sup> Møller & Husby 2000, p. 219

<sup>179</sup> Møller 2000; 7-23; "cellulaera-changes" Paul Møllers choice of word. Møller, 2000, SEPREP

<sup>&</sup>lt;sup>180</sup> Møller 2000, pp. 22-23; Møller 2001

<sup>&</sup>lt;sup>181</sup> Ibid. pp. 22-23; Møller 2001

<sup>182</sup> See for example Parnas et al. 2005

<sup>&</sup>lt;sup>183</sup> Møller & Husby 2000

# Part A

A theoretically possible interpretation of Møller's research is that once these phenomena are found – that are so intrinsic core psychosis phenomenology – the patients can be treated as having initial symptoms of schizophrenia. Møller is also focused more on the prodromes of schizophrenia rather than the more open standpoint of the other researchers concerned with different kinds of psychotic disorders.

<sup>&</sup>lt;sup>184</sup> Møller 2001, p. 11

# PART B – MATERIAL, METHOD AND TECHNIQUES













# 3 Method and material

# **EMPIRICAL MATERIAL**

# SELECTION OF PATIENTS

The study was performed in a defined area in Norway, defined both regarding population and geography. Through my position as leader of the project at a specialist psychiatric clinic I had direct and daily contact with the psychiatrist and therapist responsible during the period of data collection. All persons in the area with psychotic symptoms had the opportunity to receive help at the specialist clinic.<sup>185</sup> There was a small possibility that a patient would have such acute symptoms and progress of illness that he or she would be sent on emergency to an inpatient clinic outside the area for compulsory care, since there were no fascilities for compulsory care in the area. If that happened information about the patient would reach the clinic where I was working anyhow, since the leader of the clinic had the overall responsibility for psychiatry in the area.

For the patients to be asked to participate in the study it was required that they had had a recent first psychotic episode or that they were considered at risk of being psychotic in the near future, formally by me defined as in an active prodromal phase.

During the first phase of the study every patient that had a first-episode of psychosis or was considered to be at risk of being psychotic was included. Because of a rather low but not exceptionally low number of patients with that complex of problems in 2002 the study also included the same category of patients in 2005.

In all, eleven patients were interviewed – nine women and two men. <sup>186</sup> The total number of patients agreed with the number of expected cases that had that complex of problems during the same period in the area. The area is rather small and that is why it is unpredictable what proportion will have the same complex of problems, but an average has

<sup>&</sup>lt;sup>185</sup> I use the term "clinic" to refer to the whole organization, wich included several clinics. I was working at the specialized adult out-patient psychiatric clinic.

<sup>&</sup>lt;sup>186</sup> Another five patients did agree to take part and could have been interviewed. However because of the similarity to the first eleven patients, the last five were never included in the study.

been estimated on the basis of the total patient population in the area and national estimations of prevalence.<sup>187</sup>

This is a qualitative study with metapsychiatric ambitions, and the number of patients does not justify statistically based claims nor general conclusions. These eleven patients are the basis for analysis of the prodromal phase and its phenomenology. In the context of the results I will discuss the possible conclusions to be drawn.

It is important to underline that psychiatrists have chosen the patients for the study, I have not. It was decided that the psychiatrist responsible should make the selection of patients to ensure that it corresponded with the inclusion criteria.

All patients in this study were under treatment at a psychiatric clinic in the area. All patients had also been investigated for somatic diseases and no patient had at the time of the interviews any discovered somatic cause for their suffering.

# INFORMATION FROM MEDICAL RECORDS

The information was collected from the local system of medical records, the so-called DIPS-system.<sup>188</sup> It is partly statistical, in the form of the number of consultations per patient and categories of diagnoses, and partly descriptive, in written records. The statistical information of prevalence was also collected from a larger evaluating project performed as a part of this PhD project at the clinic in 2000-2002. The title of the evaluation is *Brukertillfredshet med behandlingen vid poliklinikker*.<sup>189</sup> The questions were developed by *Helsetilsynet* in Norway.

I did not read anything in the patient's medical record in advance of the first interviews. In some cases, though, I had sporadically got some information about the patient from participating in the daily work at the clinic.

#### THE INTERVIEWS

The interviews were qualitative open ones. They had an objective settled beforehand but as a rule as much space as possible was left for the patients to decide what to tell and how to tell it. Ten out of eleven interviews were tape-recorded and later transcribed. I transcribed most of the interviews myself as soon as possible afterwards to be able to include dimensions and details in the telling that would be as close to the actual situation as possi-

 $<sup>^{187}</sup>$  The number is based on an evaluation done on the total group of patients treated at the centre in 1999 and is also equivalent to national estimations. Neubeck & Klausen 2000

<sup>&</sup>lt;sup>188</sup> DIPS is a short version of, from the beginning: Distribuert Informasjons- og Pasientadministrativt System but today stand for: Digitalt Integrert Pasientadministrativt System.

<sup>189</sup> Neubeck & Klausen 2000

ble. A secretary that obeyed the same confidential rules as I did working at the clinic, helped with parts of the transcriptions. On those occasions I reread the transcriptions directly and was able to add anything that was missing and rectify anything that was misinterpreted. I have also reviewed all the transcriptions thoroughly to check for possible mistakes. In the case of the interviews with one patient I chose not to use the tape-recorder, but instead made notes afterwards, this out of respect for the patient in question. It was also decided, in accordance with the wish of the same patient, that the interview should be conducted at a public place not the psychiatric clinic. In the other cases the interviews were performed at the psychiatric clinic.

After every interview I analysed and wrote down thoughts and feelings in a general text.

#### INTRODUCTION TO THE INTERVIEW

At the beginning of the first interview I gave introductory information about the project. The introduction of the interviews was as follows:

I would like you to tell me why you sought psychiatric help and what psychiatric help you have received?

I would further like you to tell me about the time when things started to change, regardless of whether it was inner or external change, and to tell me about different changes that later led to your needing help.

I would like you to tell me about every change, like changes in your experiences, attitudes, interests, feelings, and contact with others, sense impressions, thoughts or anything else.

My question is not restricted to a specific period of time; you can choose any time that you feel is important, but preferably before you sought help.

You will have all the time you need for your telling, which means that this interview can last as long as you would like it to last, and we can meet several times if you wish.

I would also like to underline that what I know about you is that your psychiatrist decided you would be suitable for this study. I have not read or seen anything of your medical record.

All informants started to tell their story after this introduction and I of course asked several questions during their narration. The interviews lasted between one and eight hours. Some of course were divided into several occasions.

#### **OBTAINABILITY OF THE INFORMATION**

No patients in my study had any objection to or difficulty in talking about their experiences to me in the interview situation. The patients perceived their experiences and the correlation with what was happening to them as natural and understandable, even though the suffering and the changes in their self were chaotic and hard to endure. The fact that these patients understood the phenomena and could set them within a framework of coherence also made them believe that their traumata would play a central role in their rehabilitation and treatment. A great important difference between these interpretations and interpretations done in Chapter 4 is that the phenomena were now shown not to be a disorder of the isolated individual, but interactive with others, in a context with others.

There can be different reasons why the patients in this study so naturally told their lifestory. First, I had no part in the treatment of these patients. Even though I worked at the clinic I am not a therapist – which was made very clear at the beginning. I started the interview very openly and I did not decide what it was important to talk about except regarding a specific time – the time prior to when they needed help. This made it possible for the patient to decide what was most important to start to talk about. I did not focus, either, on specific signs, changes or symptoms but let the patients tell their story, and I tried as much as possible not to interact or influence the story. These can be some of the factors that made it possible for them to tell the stories about the abuse they had experienced. Several researchers have started to discuss the old psychoanalytic method of not regulating the patient's telling and they are able to show how much information gets lost if the doctor or therapist chooses what is important and what is not, especially very early in a process.<sup>190</sup>

#### METHODOLOGICAL CONSIDERATIONS

I have chosen not to question the validity of the stories as a whole; my concern has been the life-world of the patient and the *patient's truth*. The phenomenological interpretation concerns how the patients told me they experienced their situation in relation to their sufferings. Their truth has been my main focus of interest. It is not my concern to question the veracity of the details presented, but, as mentioned, the main facts are verified by other sources, such as medical records and statements from therapists. Again, this is a metapsychiatric study, not a medical, psychiatric or even juridical one.

<sup>190</sup> This is for example shown in Ana Luise Kirkengens research see further Kirkengen 2005; Read, Mosher & Bentall 2004; or Miller 1988 etc.

For the analysis made in this study the *experienced* violation is the most important phenomenon. Many patients told of over-involvement in relation to central objects in their growth, often while they were dependent on the objects violating them. It is obvious, though, that the violations have been dissimilar and the levels of distress have been diverse among the patients. But the main issue for this study is that the fundamental experiences of violation are true to these patients. All stories told indicate a very high level of abuse – it is beyond doubt that experiences like those would result in great suffering. To verify facts in detail is not an interest of this study. So some details may be exaggerated or actually mistaken, but everything has been experienced by the patients. Nor has there been any reason to believe that the patients were directly psychotic at the time of the interviews. During one session one patient did talk about visual illusions that could be defined as hallucinations but that was only for a moment.

Another aspect to consider is my not being a specialist in sexual abuse or violation. Nor am I a psychiatrist or a therapist. How am I to judge if these stories are true or not? I am a PhD student within the field of philosophy of science; I have my background in psychology, pedagogics, the humanities and philosophy. I have also worked, partly practically, in psychiatry for 15 years and I have been a member of staff at the clinic where this study was performed since 2000. I have got all the help needed from the staff at the clinic and from my supervisors in analysing the stories told. There is a possibility that the patients found it easier to talk to me as being neither a psychiatrist nor a therapist but only interested in their history. I did not have any power to intervene in their treatment, what they told would not have any consequences. I did not give any feedback to the psychiatrist or therapist after the interviews. I have seen it as an advantage that I was analysing these patients' stories from a perspective outside psychiatry. The stories, interviews and information have also been analysed with help of my supervisors: professor Lisbet Palmgren and professor Lennart Nordenfelt. Even so, all interpretations and any mistakes are mine.

One aim of the study was from the beginning also to include siblings of the patients as informants. This study design was approved by the relevant ethical committee in Norway but dropped by me. I made that choice since so many traumatic family stories were presented in the interviews and I did not want to interfere in the already traumatizing processes. And since this study is a metapsychiatric one focusing on the patients' life-world, in combination with a concern for the patients, I chose not to talk to the siblings.

# TECHNIQUES FOR INTERPRETATION

# **PRODROME INTERPRETATION**

Since I noted an increasing interest in early identification and intervention in the case of schizophrenia when collecting data for this thesis and as I was interested in finding out if it was possible to identify prodromes prior to a psychotic episode; I have allowed myself to choose two well-known lists of suggested prodromes, presented above and apply them to my material. I have related the lists to the empirical material in a hypothetical analysis, to see if there is any concordance.

The lists are used in this thesis as an illustration of a scenario of what could (or can) happen in the future if this kind of knowledge is used as a diagnostic tool.

All the interpretations have been made under the supervision of professor Lisbet Palmgren. The chosen texts: thoroughly presented in Chapter "Prodrome Theory", are these: Paul Møller and Ragnhild Husby's list of prodromes of schizophrenia published in the *Schizophrenia Bulletin* as well as in Paul Møller's thesis, and Jane Edwards and Patrick McGorry's list published in *Implementing Early Intervention in Psychosis*.

#### **EPP** – THE TOOL FOR PHENOMENOLOGICAL INTERPRETATION

The material has also been analysed with the qualitative and phenomenological method *Empirical Phenomenological Psychological Method* (EPP method) developed by professor Gunnar Karlsson at the University of Stockholm.<sup>191</sup> The EPP method is a qualitative tool for phenomenological analyses and derives from Husserl's phenomenological psychology. The method focuses on the classification of qualities or characters of phenomena.<sup>192</sup> The intention is to describe meaning and/or meaning structures in phenomena and the results are descriptive and subject-oriented. All phenomena analysed in this theses are experienced by an intentional subject and the method describes what the phenomenon is and how it appears for the subject. Karlsson defines the method phenomenologically and psychologically since it represents an attempt to describe the phenomena from the perspective of the subject. The results focus on the meaning of the phenomena for the subject and not merely on the phenomena itself. The eidetic phenomenology evolved by Husserl was developed as a philosophical method. There is a difference when this method is used in psychology: in psychological use there is no intention to reach a pure truth but instead

<sup>191</sup> Karlsson 1995; Karlsson 1999

<sup>192</sup> Karlsson 1999, pp. 327-355

to uncover meaning. Truth is also a problematic concept within psychology and psychiatry in general.

The reason that the method is defined phenomenologically and not hermeneutically is that the aim is not to find individual and specific structures but general structures. <sup>193</sup> Nevertheless though there are several dimensions corresponding to hermeneutical methods in EPP, for example preunderstanding the phenomena which in EPP as in hermeneutics is seen as a requirement. Also the element of a dialectic pendulum from details to entirety, described in the classical hermeneutic circle, is present in EPP. It is used in the different steps of going through the material looking for meaning units as well as general structures. A third corresponding characteristic is that the object for study has the structure of a text. In this thesis the studied object is basically transcribed interviews and medical records. It is necessary both in classical hermeneutics and in EPP to be able to go back to the material/protocol several times to deepen and redo the different steps as required.

The results that can be derived from using the EPP method are described by Karlsson as different levels. The first level is when a structure of a phenomenon is found in several protocols, then defined as general. If several structures are found of the same phenomenon they are instead defined as typological.<sup>194</sup> This is as an example given by Karlsson when a phenomenon appears in different ways in different protocols but describing the same meaning.<sup>195</sup> The general markers can also after they have been found and analysed, structured and refound in the text be tested at a higher level, level three in Karlsson's definition, and then test the structures or markers, are ontological components describing a compelling possibility for the phenomena.<sup>196</sup> To test this through Husserlian reductionism with free variation in fantasy is to test if the structure is sufficient in all imaginable variations. If the structure is sufficient it is possible with the EPP method to test if general markers for structures of meaning are actually ontological for the phenomena studied.<sup>197</sup>

Karlsson also suggests non-compelling possibilities; possibilities that are imaginable but not compelling. Such non-compelling possibilities can be called characteristics pertaining to the phenomenon in question. Compelling possibilities are, however, necessary conditions (possibilities) for the phenomenon in question.

Karlsson discusses two different approaches for the researcher to take in the process of understanding when using the EPP method. The approaches are: 198

REU – researcher's empathetic understanding

<sup>193</sup> Karlsson 1999, pp. 342-347

<sup>194</sup> Ibid., p. 348

<sup>195</sup> Ibid., p. 348

<sup>196 &</sup>quot;Compelling" in the meaning of conditions necessary for the existence of the phenomenon in question.

<sup>&</sup>lt;sup>197</sup> Karlsson 1999, p. 349

<sup>198</sup> Karlsson 1995, pp. 125-133

This is the perspective adopted by the researcher to uncover the original experience of the subject.

RIU – researcher's interpretive understanding

The perspective as interpreter of the text as autonomous vis-à-vis the subject's original experience. Here the comprehensive structures of meaning are interpreted and compared with other analysed text.

The analysis of the text has been performed in accordance with the following five steps corresponding to the EPP method:<sup>199</sup>

Step 1 – Reading through the text<sup>200</sup>

This step is open and it is important at this point to separate understanding from theory. In this step I have read through, without making too many notes, all the empirical material collected for this thesis. This has also been done stepwise. First I have read the transcribed interviews and reread them and then I have looked for further information in medical records, before I have gone to the next interview. Mostly the interviews have been transcribed directly after and I have been able to reread the transcripts prior to the second and third interviews. Sometimes I have had interviews with a patient close in time and then I have naturally transcribed the interviews after the last meeting. I have also made notes after every interview where I have written my thoughts, feelings, questions and other things regarding the meeting with the informant.

# Step 2 – Finding units of meaning

This is the basic work for further analysis and understanding. Meaning units (MU's) are not separable units which together generate the text, they are instead independent units that can be reorganized. I have looked for different MU's and themes. The overwhelming theme has been trauma in most interviews so I have here focused on different angles of the trauma reported. I have looked for relations between changed experiences such as paranoid thought, fear, situations focused on by the informant. This step is thourougly presented in Chapter 5 "Phenomenological interpretation".

#### Step 3 – Description of the MU

This is when the actual analysis begins. The phenomenological reduction is initiated and the researcher uses the eidetic induction through the interpretation – eidetic in the sense of a process of description of specific facts described in the text as to phenomenological meaning. The goal is to uncover explicit and implicit phenomenological meanings expressed by the subject. In this step I have for example described when the changes have started and which interpretation the patient has given the phenomena. I have looked for

<sup>199</sup> Karlsson 1995, pp. 93-124

<sup>&</sup>lt;sup>200</sup> Karlsson uses the term "protocol" but I have chosen to use "text", including both transcriptions from interviews and material from medical records.

explanations in the interviews that the informant has pointed out as important and then looked for overall coherence in the text. Are the topics, experiences or happenings the same as appear important in the transcriptions? What was the first topic to discuss for the informants? And did they have a coherent understanding of the situation described? Have other themes been uncovered in the interviews?

Have the stories been fragmentary and hard to analyse? In most interviews the stories have been easy to follow and to understand, in the sense that the informant has told a coherent and logical story, with a beginning and an end, and with central themes. It has not been complicated for me or professor Palmgren to read and analyse the information. The information has not been coded or covered. And most information has been checked with other sources, principally other therapists at the centre. Many themes have been discussed by the informants but nothing more essential and central than the trauma.

#### Step 4 – Collection of MU's

The reformulated MU's are reorganized in this step of the analysis MU's that belong together and MU's that express a process, for instance, are organized in samples. The researcher can now organize the MU's in a phenomenologically significant order.

I chose to start the actual writing in this step, and to formulate the results. I have maybe even more, than is recommended by Karlsson, used many quotations in order to be as close to the subject's expressions as possible. This was because I have understood the expressions as "simple" in the sense of being understandable as described above and I wanted to show how the informants told their stories.

#### Step 5 – Compilation of structures from several texts

This is the final step in the method, where general all-embracing structures are organized from several texts. This is in my view the actual analytical work, this in combination with the presentations of the interviews. I have chosen to present my interviews in two ways in this part of the analysis. I have started with a presentation of the prodrome-like phenomena found in the material from a psychiatric perspective (Chapter 4), on the basis of prodrome theories. Then I have presented a subject-oriented interpretation of the original experience in a coherent understanding of the life-world of the patient (Chapter 5). This second interpretation is done with the EPP method. I have for the sake of understanding and readability focused on the central theme – trauma – even though I have in the summary presented further themes discussed in the interviews.

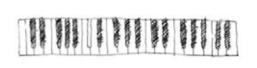
I have also chosen to present the patients one by one with an introduction of the psychiatric status of the patient at the time of the first interview, first with the prodromal interpretation. Some information is deliberately changed in some ways to guarantee confidentiality but the sex is not changed.

The EPP method has been a basis for my analyses but not a technique that I have followed in every detail. Even though the method is presented in five steps the actual process involves a constant presence of all the steps at the same time. I have constantly returned to earlier steps in the process, and constantly also gone back to the original texts to look for further details and information. This is in accordance with the method as presented in Karlsson's work. I have on the other hand not chosen to highlight sequences and meanings as much as suggested by Karlsson. I have instead focused on coherence and consistency more that on creating new categories. The coherence has been obvious from the beginning: no patient has coded anything in the telling, this despite the fact that at least one patient was obviously delusional during the interviews. All patients were diagnosed as having had severe psychiatric sufferings at the time of the interviews. For me it has been central to focus on coherencies in my further analysis.

I am not able to claim that the characteristics that I have found in the study reach the level of ontological necessity for the phenomenon in question, that is to say, they are not compelling possibilities. Instead, the characteristics can be said to be non-compelling possibilities.

The conclusion is that through the EPP method I have found non-compelling possibilities (trauma and neglect) for the phenomena (prodrome-like phenomena) to occur. In Part D I will analyse and discuss the results.

# PART C - CASE ANALYSIS



# 4 Psychiatric and possible prodrome interpretation

#### INTRODUCTION

The aim of the present analysis is to see if there were any phenomena expressed by the patients in my study that agreed with the phenomena described in the literature as prodromes of psychosis/schizophrenia. Since I found concordant phenomena I have allowed myself a *theoretical* analysis about how probable it is that these patients' suffering could be considered as prodromes of psychosis/schizophrenia. This is a presentation of how it *could be* in a psychiatric practice using prodrome literature and research. For reasons of space I have limited the presentation to five randomly selected patients, though of course a full analysis has been made of all the eleven patients with whom I was concerned. An overview of the results from the interpretations are shown in the two lists described in Chapter 4. I have chosen to limit the presentation also because I wanted as a full presentation as possible, presenting only five of the patients has enabled me to give long quotations and descriptive sections from the interviews. These five patients are chosen to exemplify the reasoning and analysis and are presented in this and the next chapter.

Preceding each presentation I give a short résumé of the patient's situation and the circumstances under which we met. Subsequently I go through phenomenon after phenomenon from the two lists and note if there are similar experiences or expressions to be found in the stories told by the patients or in their records. My interpretations have all been verified by professor of psychiatry, Lisbet Palmgren, but of course any mistakes are mine. It should further be pointed out that all the patients prior to the interviews had been diagnosed by the doctor responsible as probably being in a very early phase of psychosis/schizophrenia.

#### **ELSA - PRODROMES**

A woman in her early twenties, in the text called Elsa. At the time of the first interview she was admitted to the psychiatric clinic with hallucinations. She had been diagnosed as having schizophrenia a couple of years before. She was included in the study because she had recently been transferred to our clinic and a new investigation had started since there were ambiguities with regard to her diagnosis. She had experienced prodromes and preand borderline psychotic states, including several other symptoms and changes during a relatively long period according to her medical record. At the time of the interviews she was not actively psychotic but clearly affected and because of that in need of constant support. She was quite withdrawn and walked with a heavy gait and a stooping posture. She acted lethargically and did not initially establish any eye contact. She mentioned problems with many bodily functions as well as with psychological functions which made it difficult for her to manage on her own. She was living with sophisticated support from the psychiatric organization in the community. Over the years she had furthermore been treated at many institutions in Norway and been investigated for lowered cognitive ability, other deficiencies in her development, emotional immaturity, deficient social relations and so forth.<sup>201</sup> Her family relations were very poor. She was often made use of in economic circumstances, and her life was, as described by her and her medical record, exposed and lonely. 202

In this case I have limited the period for identifying phenomena to the time prior to and during her first school years, which is the time prior to when she experienced her first diagnosed psychotic episode. She had heard voices since her seventh year but was uncertain when everything started. She claimed that it had always been like this.

Using Edwards and McGorry's list revealed the following concordance:

#### 1. Reduced concentration, attention

She described difficulty in concentrating at school to the degree that she received medicine to improve her ability.<sup>203</sup>

#### 2. Reduced drive and motivation, anergia

She described lack of ability to begin things and said that she walked sloppily when she did not feel well.<sup>204</sup>

<sup>&</sup>lt;sup>201</sup> Elsa medical record, passim

<sup>202</sup> Ibid., 2:10

<sup>&</sup>lt;sup>203</sup> Ibid., 2:5

#### 3. Depressed mood

She regarded herself and her situation as hopeless and she was convinced that her life would turn out badly.  $^{205}$ 

# 4. Sleep disturbance

She regularly had difficulty to sleep but when she eventually fell asleep she slept so deeply that she needed help to get up in the morning.<sup>206</sup>

#### 5. Anxiety

She believed everything she did was wrong and that people around her said unpleasant things about her. The voices she heard also had many bad things to say about her. <sup>207</sup> She was afraid that witches and such creatures would harm her. <sup>208</sup>

#### 6. Social withdrawal

She told of her problems at school with regard to finding friends and said that she was teased if not directly bullied by other children.<sup>209</sup>

#### 7. Suspiciousness

She claimed that she always believed others would hurt her and she felt unsafe all the time. 210

#### 8. Deterioration in role functioning

She reported a feeling of being able to lift away from her own body. She called this the technique of flying. She also told of dark shadows that "came over" her.<sup>211</sup>

#### 9. Irritability

She did not tell me – neither is it reported in her medical record – that she felt unduly irritated.

<sup>&</sup>lt;sup>204</sup> Elsa, 1:7

<sup>205</sup> Ibid., 1:2f

<sup>206</sup> Ibid., 1:8

<sup>&</sup>lt;sup>207</sup> Ibid., medical record, and 1:1ff

<sup>208</sup> Ibid., 1:3ff; 2:1ff

<sup>209</sup> Ibid., 1:3f

<sup>210</sup> Ibid., 1:3

<sup>211</sup> Ibid., 1: 2ff

In summary: from the information received from Elsa and her medical record I identified eight out of nine phenomena that agreed with Edwards and McGorry's list of prodromes of psychosis. Accordingly, it is theoretically possible to interpret Elsa as presenting eight out of nine phenomena of a forthcoming psychosis according to Edwards and McGorry's list.

	Edwards and McGorry	Elsa
1	Reduced concentration, attention	X
2	Reduced drive and motivation, anergia	X
3	Depressed mood	X
4	Sleep disturbance	X
5	Anxiety	X
6	Social withdrawal	X
7	Suspiciousness	X
8	Deterioration in role functioning	X
9	Irritability	

Using Møller's list revealed the following concordance:

# 1. Disturbance of perception of self

She did not say anything indicating that something was directly wrong with her nor that something had drastically changed.

#### 2. Extreme preoccupation with and withdrawal to overvalued ideas

In her own world she had had another family with two brothers. One brother was a spirit of the woods and the other a spirit of the sea. Both brothers eventually died, one as a result of environmental pollution. When her brothers died she was haunted by a devil that stayed with her constantly.<sup>212</sup>

She said that she one day saw an angel in her room and she thought she was dead. She further spoke about ghosts that she had seen in her father's house.<sup>213</sup>

#### 3. Neurotic-like disturbances

She reported difficulty to sleep and sleeping very heavily in the morning. She often felt anxiety and tried to conceal her feelings in order not to be revealed as ill.<sup>214</sup>

<sup>&</sup>lt;sup>212</sup> Elsa 1:4

<sup>213</sup> Ibid., 1:2ff; passim

<sup>214</sup> Ibid., 1: passim; 1:8

# 4. Disturbance of formal thought

She described difficulty in concentrating at school to the degree that she received medicine to improve her ability.<sup>215</sup>

# 5. Attenuated delusional ideas or perceptions

Events she told about, like sexual abuse, were verified by the psychiatric nurse accompanying her at the interviews. Elsa spoke about witches and other creatures but it turned out to be stories told by her uncle to force her into silence. It is doubtful whether these perceptions really can be interpreted as hallucinations or delusions but I have chosen to include them here.

#### 6. Disturbance of mental/inner control

She told me that she could not control her fear and anxiety. She had reacted violently. See incident at the pool in 8, below.

# 7. Secondary coping/relieving responses

I found no concordance in the interview or in her medical record.

# 8. Disturbance of simple perception

She described how she once sat at a pool with her classmates and perceived that they became refined and "cultivated". <sup>216</sup> It all started with her hearing music both Norwegian and foreign. The music communicated with her and later she also heard voices. Then she believed that the voices actually made the music in her head.

She said that she became afraid when she saw things in reality that were in accordance with her inner pictures. The voices culminated on her first day at school.<sup>217</sup>

In summary: from the information received from Elsa and information I found in her medical record I identified six out of eight phenomena that agreed with Møller's list of prodromes of psychosis. Accordingly, it is theoretically possible to interpret Elsa as presenting six out of eight phenomena of a forthcoming psychosis according to Møller's list.

<sup>&</sup>lt;sup>215</sup> Elsa 2:5

<sup>216</sup> Ibid., 1:3ff

<sup>&</sup>lt;sup>217</sup> Ibid., 1:2

	Møller	Elsa
1	Disturbance of perception of self	
2	Extreme preoccupation with and withdrawal to overvalued ideas	X
3	Neurotic-like disturbances	X
4	Disturbance of formal thought	X
5	Attenuated delusional ideas or perceptions	X
6	Disturbance of mental/inner control	X
7	Secondary coping/relieving responses	
8	Disturbance of simple perception	X

# **TOVE - PRODROMES**

A young woman, in the text called Tove, was found confused by passer-by, at a small harbour on the verge of throwing herself into the water, and an ambulace was called. She spoke incoherently and appeared disoriented. She weighed only 45 kilos and it was difficult to establish contact with her. Her symptoms were classified as prodromes with elements of prepsychotic delusion and she was investigated for possible schizophrenia. She had newly arrived in the area. She had obvious difficulty in following a conversation and medical staff suspected hallucinations.<sup>218</sup> She reported that she slept more than normally and had difficulties with her daily rhythm.<sup>219</sup> She had simply forgotten to eat and lost a lot of weight, which confused her. The interviews with her were chaotic and incoherent and she had great difficulty in concentrating.

During the interviews she reported that everything started with her increasing forgetfulness. She forgot to eat and to clean her teeth. This gave her a bad conscience and she became irritated with herself. She believed people around her talked about her and that she did not have any friends.<sup>220</sup>

She had been regularly in contact with a welfare officer since maybe her first year in school but could not remember exactly. As was the case with Elsa and a person not presented here, Rakel, she had started having problems so early in life that she could not recall a "prior to". She described a feeling from her fourth year in school:

<sup>&</sup>lt;sup>218</sup> Tove medical record

<sup>219</sup> Ibid., 1:1

<sup>220</sup> Ibid., 1:ff; introduction

Sometimes I just got so very sad. I just was. Just cried and cried and cried. I was so very sad. And I wasn't sure what it was either ...  $^{221}$ 

And that in the back of my head I just feel or hear what people say, and then I think, in a way, what do they think about me now, or do they look at me strangely; or it could happen that I think that everybody is against me. I just have the feeling that everybody is just pretending that they are my friends  $\cdots$  I just get the sense that I actually have no friends. 222

She had always had a feeling of being out of it, never really being accepted anywhere.<sup>223</sup> She spoke about woodpeckers in her head that she could not get rid of, the woodpeckers pecked and pecked at the thoughts in her head.<sup>224</sup> She also told of a chaotic family situation with several family members with a psychiatric diagnosis.<sup>225</sup>

I have identified her prodromal phase til the time prior to the first admission to a psychiatric hospital, which was in accordance with the time for the first interview.

Using Edwards and McGorry's list revealed the following concordance:

#### 1. Reduced concentration, attention

She described how she started to forget things, did not manage to remember. 226

# 2. Reduced drive and motivation, anergia

She felt she had been walking around sleeping, she had had a hard time taking care of her own hygiene, she had stopped taking showers, stopped cleaning her teeth.<sup>227</sup>

# 4. Sleep disturbance

She slept a great deal, turned day into night and night into day.<sup>228</sup>

#### 5. Anxiety

She had felt a great deal of anxiety about almost everything, for example that her boy-friend would be unfaithful, that she had lost her friends, that she would be all alone.<sup>229</sup>

<sup>&</sup>lt;sup>221</sup> Tove 1:8

<sup>&</sup>lt;sup>222</sup>Ibid., 1:2

<sup>&</sup>lt;sup>223</sup> Ibid., 1:8

<sup>&</sup>lt;sup>224</sup> Ibid., 1:3

<sup>225</sup> Ibid., 1:ff; 2:ff

<sup>226</sup> Ibid., 1:1

<sup>&</sup>lt;sup>227</sup> Ibid., 1:1

<sup>228</sup> Ibid., 1:1f

<sup>229</sup> Ibid., 1; 2; 3 passim

#### 6. Social withdrawal

Had stayed at home, had not had the energy to be with friends, felt insecure and unpleasant socially.<sup>230</sup>

# 7. Suspiciousness

She described how she had felt that she had no friends; she dreamt her boyfriend was unfaithful.<sup>231</sup> She had also believed that people were talking about her behind her back when she went out with friends, and in the back of her head she had been able to hear what they had been saying.<sup>232</sup>

# 8. Deterioration in role functioning

She described a feeling of not knowing who she was. She said that she had had a hard time knowing if her friends were her real friends or just acting as friends.<sup>233</sup>

#### 9. Irritability

She had started to feel an irritation about herself, started to neglect herself and be sloppy, felt frustration.<sup>234</sup> She told how she had been wandering around with a snarl inside, she had felt so angry.<sup>235</sup>

In summary: from the information received from Tove and her medical record I identified nine out of nine phenomena that agreed with Edwards and McGorry's list of prodromes of psychosis. Accordingly, it is theoretically possible to interpret Tove as presenting all the phenomena of a forthcoming psychosis according to Edwards and McGorry's list.

<sup>&</sup>lt;sup>230</sup> Tove 1:1ff

<sup>231</sup> Ibid., 1; 2; 3 passim

<sup>232</sup> Ibid., 2ff

<sup>233</sup> Ibid., 1:1ff

<sup>&</sup>lt;sup>234</sup> Ibid., 1:1

<sup>235</sup> Ibid., 1:13

	Edwards and McGorry	Tove
1	Reduced concentration, attention	X
2	Reduced drive and motivation, anergia	X
3	Depressed mood	X
4	Sleep disturbance	X
5	Anxiety	X
6	Social withdrawal	X
7	Suspiciousness	X
8	Deterioration in role functioning	X
9	Irritability	X

Using Møller's list revealed the following concordance:

# 1. Disturbance of perception of self

She described a feeling of not knowing who she was. She said that she had had a hard time knowing if her friends were her real friends or just acting as friends.<sup>236</sup>

# 2. Extreme preoccupation with and withdrawal to overvalued ideas

She had been extremely preoccupied with what other people had thought about her, she heard what other people were saying in the back of her head.<sup>237</sup>

#### 3. Neurotic-like disturbances

She felt she had been walking around sleeping. She described how she had felt unsuccessful, not able to do anything, not having the energy to do anything, had a guilty conscience. Lost weight, neglected her hygiene, experienced sleeping disturbances, slept a very great deal and felt a great anxiety. She had also felt irritation, was sloppy and felt frustrated.<sup>238</sup>

# 4. Disturbance of formal thought

She described how she forgot things, she was not able to remember.<sup>239</sup>

# 5. Attenuated delusional ideas or perceptions

She had been preoccupied with what other people thought about her, said about her, and she heard what they said. She dreamt she was abandoned, totally alone. 240

<sup>&</sup>lt;sup>236</sup> Tove 1:1ff

<sup>&</sup>lt;sup>237</sup> Ibid., 1:2ff

<sup>238</sup> Ibid., 1:1

<sup>239</sup> Ibid., 1:1

#### 6. Disturbance of mental/inner control

She spoke about woodpeckers that pecked and pecked at her thoughts.<sup>241</sup>

# 7. Secondary coping

She had taken drugs and tried to make herself invisible in social settings.<sup>242</sup>

# 8. Disturbance of simple perception

I found no concordance in the interviews or in her medical record.

In summary: from the information received from Tove and information I found in her medical record I identified seven out of eight phenomena that agreed with Møller's list of prodromes of psychosis. Accordingly, it is theoretically possible to interpret Tove as presenting seven out of eight phenomena of a forthcoming psychosis according to Møller's list.

	Møller	Tove
1	Disturbance of perception of self	X
2	Extreme preoccupation with and withdrawal to overvalued ideas	X
3	Neurotic-like disturbances	X
4	Disturbance of formal thought	X
5	Attenuated delusional ideas or perceptions	X
6	Disturbance of mental/inner control	X
7	Secondary coping/relieving responses	X
8	Disturbance of simple perception	

# **ODD-BJARNE – PRODROMES**

A young man, in the text called Odd-Bjarne, had been treated for indefinable problems. He had sleeping disturbances, problems with waking up, did not cope at work etc. He also described sudden "attacks", quite like epilepsy. He became unconscious and fell over, his body shaking. He described an inability to cope with life in general. He had great pain

<sup>&</sup>lt;sup>240</sup> Tove., 1

<sup>241</sup> Ibid., 1:3f-13

<sup>242</sup> Ibid., 1:1, passim

in his face after a car accident and he struggled with a lot of flashbacks from the accident, and after the accident he had had great difficulties with public authorities.<sup>243</sup> He was at the time of the interview being investigated for schizophrenia.<sup>244</sup> He described how after the accident everything "had gone to being hell":

Everything is hell ... I can't get any sleep, I keep waking up ... now this is an exception ... but usually I'll wake up at in the middle of the night, cold but sweating, having nightmares about the accident or other similarly odd dreams, and can wake up with withdrawal symptoms and shivering<sup>245</sup> and when I wake up it is just like I am chewing and crushing my jaws, the teeth fall out of my mouth, and that is also how it feels.<sup>246</sup>

He said that he often woke up from dreams where he re-lived the accident, his head being thrown against the steering wheel at great speed. He could not get in control of his situation. This is how he illustrated why he did not want to keep his car:

No, I can't afford it, and I don't have the nerve to drive. I've known that for a long time now, but I never believed it ... I don't actually take myself seriously. In fact I've never given a shit about myself mentally.<sup>247</sup>

He described the difference between prior to and after the accident:

Prior to the accident I really didn't have any [problems]. I don't know, everything just went along. 248

He continued when I asked if he had not had any problems at all prior to the accident:

Oh, I had ordinary problems, but not this kind of problems. Maybe I had a hard time sleeping once a month, and I'm not talking about five minutes to go to sleep, I'm talking about several hours. I know it is guaranteed that I would have problems after the accident. My head feels like a big fucking sore.<sup>249</sup>

I was a bit dizzy after the accident, but in another way not dizzy. I don't fucking know, it is just weird. 250

I asked how much he was injured in the head by the accident:

<sup>&</sup>lt;sup>243</sup> Odd-Bjarne interviews passim

<sup>&</sup>lt;sup>244</sup> Ibid., medical record; 1:2

<sup>&</sup>lt;sup>245</sup> His called them "nökkinger".

<sup>246</sup> Odd-Bjarne 1:2

<sup>&</sup>lt;sup>247</sup> Ibid., 1:3

<sup>248</sup> Ibid., 1:3

<sup>&</sup>lt;sup>249</sup> Ibid., 1:3

<sup>250</sup> Ibid., 1:7

Well, my head went through the windscreen. The windscreen was like a giant football. But a strange thing has been happening in my head since the accident. I can't tell exactly what but it is weird. But I think it has a lot to do with the accident. And then there are the splinters in my face because of the accident. So a lot of time I've just wanted to kill myself and be done with it, and escape everything and the state will be spared from losing money.<sup>251</sup>

#### He described how it was to feel good:

No, it feels good because I don't have all the dark clouds up here. Felt more secure about life was going to be good, maybe. Hell, I don't know ... I just know it was better before. Ugh ...  $^{252}$ 

He wanted to have a disability pension since he felt he just failed everything he had tried to do the last couple of years. He had given up hope of finding a solution to his situation other than disability pension. He had just turned 20 at the time of the interviews.

I have decided to take his prodromal phase as corresponding to the time of the interviews, since he was then under investigation for schizophrenia, but had not been diagnosed as having any psychotic symptoms.

Using Edwards and McGorry's list revealed the following concordance:

#### 1. Reduced concentration

He said that he had difficulty in concentrating.<sup>253</sup>

#### 2. Reduced drive and motivation

He had problems with waking up in the morning, he was not able to get up until it was necessary and then he had to go directly to work.<sup>254</sup>

#### Depressed mood

He described how everything had gone to hell.<sup>255</sup> He felt like a B-type person.<sup>256</sup> He tried to be regarded as disabled at the age of 20 to "normalize" life.<sup>257</sup> He spoke about an urge to commit suicide as a solution to all the problems.<sup>258</sup> He had made one suicide attempt.<sup>259</sup>

<sup>251</sup> Odd-Bjarne 1:7

<sup>&</sup>lt;sup>252</sup> Ibid., 1:9

<sup>253</sup> Ibid., 1:7

<sup>254</sup> Ibid., 1:5; and my first meeting with him.

<sup>255</sup> Ibid., 1:2

<sup>256</sup> Ibid., 1:5

<sup>257</sup> Ibid., 1:6

<sup>258</sup> Ibid., 1:7

# 4. Sleep disturbance

He woke up at night in a cold sweat after having had nightmares, and when he woke up he had felt withdrawal symptoms and was shaking. He told of how he sometimes woke up and was exhausted because of the way he was, and he felt like he just wanted to sleep and then he knew he had started to get problems coping with ordinary things.<sup>260</sup>

# 5. Anxiety

He lost his sense of security and he experienced dark shadows over his head when he started to feel ill.<sup>261</sup>

#### 6. Social withdrawal

When he started to feel ill he just went under his duvet and tried to dream the time away. He did not want to have contact with anyone or do anything else than lie there, still, and explore his inner self. Sometimes he had not left his bed for days.<sup>262</sup>

# 7. Suspiciousness

He thought the whole of society was after him. That all the public authorities did all they could to get hold of him and cause him problems.<sup>263</sup>

#### 8. Deterioration in role functioning

He said there was something strange about him. He had had strange shakings in his body and felt bizarre in his head. <sup>264</sup> He felt like a B-type person. <sup>265</sup>

#### 9. Irritability

I found no concordance in the information or interviews.

In summary: from the information received from Odd-Bjarne and his medical record I identified eight out of nine phenomena that agreed with Edwards and McGorry's list of prodromes of psychosis. Accordingly, it is theoretically possible to interpret Odd-Bjarne

<sup>259</sup> Odd-Bjarne 1:10

<sup>&</sup>lt;sup>260</sup> Ibid., 1: passim

<sup>&</sup>lt;sup>261</sup> Ibid., 1:9

<sup>262</sup> Ibid., 2:8

<sup>263</sup> Ibid., 1; 2 passim

<sup>264</sup> Ibid., 2:7f

<sup>&</sup>lt;sup>265</sup> Ibid., 1:5f

as presenting eight out of nine phenomena of a forthcoming psychosis according to Edwards and McGorry's list.

	Edwards and McGorry	Odd-
		Bjarne
1	Reduced concentration, attention	X
2	Reduced drive and motivation, anergia	X
3	Depressed mood	X
4	Sleep disturbance	X
5	Anxiety	X
6	Social withdrawal	X
7	Suspiciousness	X
8	Deterioration in role functioning	X
9	Irritability	

Using Møller's list revealed the following concordance:

# 1. Disturbance of perception of self

He described it as being as if something was bizarre. He had these strange shakings in his body and felt bizarre in his head. <sup>266</sup> Felt like a B-type of person. <sup>267</sup>

# 2. Extreme preoccupation with and withdrawal to overvalued ideas.

He was preoccupied with the accident. The accident happened a couple of years ago, he had not got any insurance money, and he was thinking about the accident all the time. <sup>268</sup>

#### 3. Neurotic-like disturbances

He spoke about sleep disturbances, often woke up from nightmares, found it hard to initiate things and felt unmotivated.<sup>269</sup>

# 4. Disturbance of formal thought

He described concentration problems and problems with regard to getting things done.<sup>270</sup>

<sup>&</sup>lt;sup>266</sup> Odd-Bjarne 2:7f

<sup>&</sup>lt;sup>267</sup> Ibid., 1:5f

<sup>268</sup> Ibid., 2:3 ff

<sup>269</sup> Ibid., 1:5; 1:2

<sup>&</sup>lt;sup>269</sup> Ibid., 1:1f; 1:5; 1:7; 1:10; 1:2

# 5. Attenuated delusional ideas or perceptions

He spoke a lot about how the authorities had not believed him after the accident, he had not got any compensation even though it was obvious according to him that the driver of the other car should compensate him. He had also expected to get compensation for lost years of working capacity.<sup>271</sup>

# 6. Disturbance of mental/inner control

This dimension is concordant with dimension number 8. He told how he had not been able to control his shakings and attacks if he did not take his medicine. There was no brain damage found by any of the hospitals where he was treated after the accident.<sup>272</sup>

#### 7. Secondary coping

He had been drinking a lot of alcohol. 273

#### 8. Disturbance of simple perception

He described how he reacted to strong lights and flickering from his computer.<sup>274</sup>

In summary: from the information received from Odd-Bjarne and information I found in his medical record I identified eight out of eight phenomena that agreed with Møller's list of prodromes of psychosis. Accordingly, it is theoretically possible to interpret Odd-Bjarne as presenting all the phenomena of a forthcoming psychosis according to Møller's list.

	Møller	Odd-Bjarne
1	Disturbance of perception of self	X
2	Extreme preoccupation with and withdrawal to overvalued ideas	X
3	Neurotic-like disturbances	X
4	Disturbance of formal thought	X
5	Attenuated delusional ideas or perceptions	X
6	Disturbance of mental/inner control	X
7	Secondary coping/relieving responses	X
8	Disturbance of simple perception	X

<sup>270</sup> Odd-Bjarne., 1:7ff

<sup>&</sup>lt;sup>271</sup> Ibid., 2:5

<sup>&</sup>lt;sup>272</sup> Ibid., medical record

<sup>&</sup>lt;sup>273</sup> A bit uncertain whether it was often or more seldom. Odd-Bjarne, passim

<sup>274</sup> Odd-Bjarne 2:6

#### LIV - PRODROMES

A young woman, in the text called Liv, came to the psychiatric hospital in a state of crisis as she had not been able to cope with her pregnancy. She had been confused and scared in combination with the fact that she had not been able to take her ordinary medicines because of the pregnancy, and her mental state had dramatically detoriated. She was known in the psychiatric system and had been in contact several times over the last few years. She had been considered a confused, borderline psychotic and had had a long prodromal phase with some psychotic outbursts, according to her medical record.<sup>275</sup> At the time of the interviews she was on benzodiazepine as she got panic attacks and experienced mental agony in stressful situations. She had had a hard time handling her studies at a local school and she was also having problems in the relationship with the man she was living with. He was not originally from Norway and she had taken on a lot of responsibilities because of his situation as an immigrant. She had experienced other episodes of confusion where she had been wandering about and she could not be contacted. She had several times pleaded for help at the local psychiatry centre and asked them for help when she was no longer able to cope with her situation. She had several family members with a psychiatric diagnosis, involving suicide and great violence. She had at the time of her contact with the specialized unit severe sleeping disturbances and relationship problems with regard to her boyfriend, doctors and teachers. At the time of the interview her son had been born and placed in foster care.

I have decided to take her prodromal phase as corresponding with the time prior to her first diagnosed psychotic episode, which was when she was at upper secondary school.

Using Edwards and McGorry's list revealed the following concordance:

#### 1. Reduced concentration

She described how hard it was to cope in school<sup>276</sup> and how problematic it was for her to concentrate during the lessons.<sup>277</sup>

# 2. Reduced drive and motivation

She had had difficulty in making herself go to her lessons.<sup>278</sup>

<sup>&</sup>lt;sup>275</sup> Liv medical record

<sup>&</sup>lt;sup>276</sup> "School" referes to her upper secondary school period.

<sup>&</sup>lt;sup>277</sup> Since these interviews were not tape recorded all my notes will look as follows. Liv passim and information from the medical record

<sup>&</sup>lt;sup>278</sup> Ibid., passim and information from the medical record

# 3. Depressed mood

Had tried to drown herself in the sea, expressed a clear wish not to live any longer. Described herself as depressed.<sup>279</sup>

# 4. Sleep disturbance

She described how she had been sleeping and not been able to get up, she had wanted to sleep in order to get help, eventually she had slept so heavily that her schoolmates had to call for an ambulance to take her to the hospital.<sup>280</sup>

#### 5. Anxiety

She had felt a lot of anxiety concerning what life would bring her and what would and could happen to her.<sup>281</sup>

#### 6. Social withdrawal

She tells of how hard a time she has had to get friends since she moved to Northern Norway, she has been regarded as withdrawn and been bullied primarily by teachers throughout her school time.<sup>282</sup>

# 7. Suspiciousness

She describes how she has felt that her teacher at the art school and her doctors were in a conspiracy against her. She reveals that her doctors gave her teacher the responsibility for her medicines, the teacher then forced her to take her medicines in front of her school-mates.<sup>283</sup>

# 8. Deterioration in role functioning

She described how she lost control of her inner life and was "unplugged", she still had the ability to unplug. The doctors and the teacher had regarded her as psychotic and depressed and she had been admitted to the psychiatric specialist unit on emergency. She saw the situation as in terms of pleading for help but it is uncertain whether anybody heard the plea. She believed she had expressed her need but nobody had listened.

<sup>&</sup>lt;sup>279</sup> Liv passim and information from the medical record

<sup>&</sup>lt;sup>280</sup> Ibid., passim and information from the medical record

<sup>&</sup>lt;sup>281</sup> Ibid., passim and information from the medical record

<sup>&</sup>lt;sup>282</sup> Ibid., passim and information from the medical record

<sup>&</sup>lt;sup>283</sup> Ibid., passim and information from the medical record

# 9. Irritability

I found no concordance in the interviews or in her medical record.

In summary: from the information received from Liv and her medical record I identified eight out of nine phenomena that agreed with Edwards and McGorry's list of prodromes of psychosis. Accordingly, it is theoretically possible to interpret Liv as presenting eight out of nine phenomena of a forthcoming psychosis according to Edwards and McGorry's list.

	Edwards and McGorry	Liv
1	Reduced concentration, attention	X
2	Reduced drive and motivation, anergia	X
3	Depressed mood	X
4	Sleep disturbance	X
5	Anxiety	X
6	Social withdrawal	X
7	Suspiciousness	X
8	Deterioration in role functioning	X
9	Irritability	

Using Møller's list revealed the following concordance:

#### 1. Disturbance of perception of self

She told how her brain unplugged and stopped functioning in situations with too much stress.<sup>284</sup>

2. Extreme preoccupation with and withdrawal to overvalued ideas.

I found no concordance in the interviews or in her medical record.

#### 3. Neurotic-like disturbances

Had tried to drown herself in the sea, had expressed a clear wish not to live any longer. Described herself as depressed.<sup>285</sup> She had had difficulty in making herself go to the lessons.<sup>286</sup> She described how she had slept and then not been able to get up, she had wanted

<sup>284</sup> Liv 1-2:passim

<sup>&</sup>lt;sup>285</sup> Ibid., 1-2:passim and information from the medical record

<sup>&</sup>lt;sup>286</sup> Ibid., 1-2:passim and information from the medical record

to sleep in order to get help, eventually she had slept so heavily that her schoolmates had to call for an ambulance to take her to the hospital.<sup>287</sup> Expressed a lot of mental agony about how to cope with life.<sup>288</sup>

# 4. Disturbance of formal thought

Problems with concentration and coping in school.<sup>289</sup>

# 5. Attenuated delusional ideas or perceptions

She describes how she has felt her teacher at the art school and doctors had a conspiracy against her. She reveals that her doctors gave her teacher the responsibility for her medicines, and the teacher then forced her to take her medicine in front of her schoolmates.<sup>290</sup>

#### 6. Disturbance of mental/inner control

She believed she had asked for help since she was not coping both from her schoolmates and others.<sup>291</sup>

# 7. Secondary coping

It was noted in the record that she had been drinking a lot of alcohol and been taking a lot of medical drugs.<sup>292</sup>

#### 8. Disturbance of simple perception

She told a story of how she believed she was kidnapped by an UFO.<sup>293</sup>

In summary: from the information received from Liv and the information I found in her medical record I identified seven out of eight phenomena that agreed with Møller's list of prodromes of psychosis. Accordingly, it is theoretically possible to interpret Liv as presenting seven out of eight phenomena of a forthcoming psychosis according to Møller's list.

<sup>&</sup>lt;sup>287</sup> Liv passim and information from the medical record

<sup>&</sup>lt;sup>288</sup> Ibid., passim and information from the medical record

<sup>&</sup>lt;sup>289</sup> Ibid., passim and information from the medical record

<sup>&</sup>lt;sup>290</sup> Ibid., passim and information from the medical record

<sup>&</sup>lt;sup>291</sup> Ibid., passim and information from the medical record

<sup>292</sup> Ibid., medical record

<sup>&</sup>lt;sup>293</sup> Ibid., passim and information from the medical record

	Møller	Liv
1	Disturbance of perception of self	X
2	Extreme preoccupation with and withdrawal to overvalued ideas	
3	Neurotic-like disturbances	X
4	Disturbance of formal thought	X
5	Attenuated delusional ideas or perceptions	X
6	Disturbance of mental/inner control	X
7	Secondary coping/relieving responses	X
8	Disturbance of simple perception	X

# SKJALG - PRODROMES

Man in his late teens, in the text called Skjalg, who lived in sheltered accommodation. He described how he had started to feel something was changing when he was about fifteen years old. He had had delusions and had contacted the child psychiatric clinic mostly because he thought he was drinking too much. He had not been able to stop the drinking, despite long and frequent contact with psychiatric personnel. He had continued the psychiatric sessions and after he had turned 18 he was admitted to the adult psychiatric clinic. He had also been at the in-patient clinic for some time a couple of years prior to the interview.

When he was fifteen he changed, he started to see shadows and hear voices when he was alone at sea for example. He had been active in a religious youth organization and prior to the change had been coping well in school. He lived with his mother in a village by a fjord until he moved away from home to start at another school. That was at the same time as the changes started. His parents were divorced but he had many close relatives near by.

I have decided to take his prodromal phase as corresponding to the time he turned 17 and was diagnosed as having his first psychotic episode.

Using Edwards and McGorry's list revealed the following concordance:

#### 1. Reduced concentration

He described how he started to get problems with concentration in school and eventually he had to leave school. This was rather a long process but in the end he was offered the chance to try work training instead of going to school.<sup>294</sup>

#### 2. Reduced drive and motivation

He continued with school even though he could have stopped. He did not have any motivation to work either, he could not handle working, and he also described how hard it was to motivate himself to stop drinking.<sup>295</sup>

#### 3. Depressed mood

I found no concordance in the interview or medical record.

# 4. Sleep disturbance

He told of sleeping disturbances since he believed there were people outside his window at night.<sup>296</sup>

#### 5. Anxiety

He told of a situation where he had been very afraid when he was in the woods and heard people talking about him, and he started to look for the people talking but could not find anyone; he described the fear he felt and how he had contacted his family and pleaded for help. He also expressed a lot of anxiety about his thoughts and delusions.<sup>297</sup>

#### 6. Social withdrawal

He described himself as self-conscious and withdrawn during this period, "socially shy". 298

#### 7. Suspiciousness

He describes a situation at sea when he heard voices talking about him, he went on shore but found no one.<sup>299</sup>

<sup>294</sup> Skjalg passim

<sup>295</sup> Ibid., passim

<sup>296</sup> Ibid., 1:4

<sup>&</sup>lt;sup>297</sup> Ibid., 1:4

<sup>&</sup>lt;sup>298</sup> Ibid., 1:9

<sup>299</sup> Ibid., 1:4

# 8. Deterioration in role functioning

Problems coping in school and in other situations where he expected to be able to cope. 300

# 9. Irritability

I found no concordance in the interview or medical record.

In summary: from the information received from Skjalg and his medical record I identified seven out of nine phenomena that agreed with Edwards and McGorry's list of prodromes of psychosis. Accordingly, it is theoretically possible to interpret Skjalg as presenting seven out of nine phenomena of a forthcoming psychosis according to Edwards and McGorry's list.

	Edwards and McGorry	Skjalg
1	Reduced concentration, attention	X
2	Reduced drive and motivation, anergia	X
3	Depressed mood	
4	Sleep disturbance	X
5	Anxiety	X
6	Social withdrawal	X
7	Suspiciousness	X
8	Deterioration in role functioning	X
9	Irritability	

Using Møller's list revealed the following concordance:

# 1. Disturbance of perception of self

He said that something had changed but he did not know what it was. He did not give any details about whether it was an inner change or not.<sup>301</sup>

Extreme preoccupation with and withdrawal to overvalued ideas
 He described a fear of his thoughts being able to tear down his house.<sup>302</sup>

<sup>300</sup> Skjalg 1:8

<sup>301</sup> Ibid., passim

<sup>302</sup> Ibid., 1:7

#### 3. Neurotic-like disturbances

Problems in coping with school, and later work, unmotivated to stop drinking.<sup>303</sup> He described sleeping disturbances arising from the fact that he believed there were people outside his window at night.<sup>304</sup>

# 4. Disturbance of formal thought

In accord with Edwards and McGorry's number 1.

He described how he started to get problems with concentration in school and eventually he had to leave school. This was rather a long process but in the end he was offered the chance to try work training instead of going to school.<sup>305</sup>

# 5. Attenuated delusional ideas or perceptions

In accord with Edwards and McGorry's number 7.

He described a situation at sea when he heard voices talking about him, he went on land but found no one.<sup>306</sup>

#### 6. Disturbance of mental/inner control

He said that he had had so many thoughts in his head that he was unable to cope in school or with work. These thoughts in his head lived their own life and he could not decide what to think.<sup>307</sup>

# 7. Secondary coping

His large alcohol consumption, which he could not control. 308

#### 8. Disturbance of simple perception

Skjalg described it as seeing something invisible.<sup>309</sup> He also said he had seen witches and shadows.<sup>310</sup> He could feel something was in the room even if it was not visible.<sup>311</sup>

<sup>303</sup> Skjalg passim

<sup>304</sup> Ibid., 1:4

<sup>305</sup> Ibid., 1:8ff

<sup>306</sup> Ibid., 1:4

<sup>307</sup> Ibid., 1:9

<sup>308</sup> Ibid., 1: 1ff

<sup>&</sup>lt;sup>309</sup> Ibid., 1:7

<sup>310</sup> Ibid., 1:7

<sup>311</sup> Ibid., 1:7

In summary: from the information received from Skjalg and information I found in his medical record I identified eight out of eight phenomena that agreed with Møller's list of prodromes of psychosis. Accordingly, it is theoretically possible to interpret Skjalg as presenting all the phenomena of a forthcoming psychosis according to Møller's list.

	Møller	Skjalg
1	Disturbance of perception of self	X
2	Extreme preoccupation with and withdrawal to overvalued ideas	X
3	Neurotic-like disturbances	X
4	Disturbance of formal thought	X
5	Attenuated delusional ideas or perceptions	X
6	Disturbance of mental/inner control	X
7	Secondary coping/relieving responses	X
8	Disturbance of simple perception	X

#### CONCLUSION

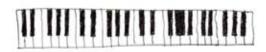
In summary, the information found in the medical records and the interviews is as follows. It is striking how great the concordance was between the lists and information in the interviews and medical records. There are two phenomena that were not found as often as the others: Edwards and McGorry's number 9 – irritability – and Møller's number 7 – secondary coping. In the case of Møllers number 7 it can be explained by the fact that these patients' changes started so early that secondary coping by means of alcohol or drugs was never an alternative.

Edwards and McGorry:

	Bente	Rakel	Heidi	Odd-Bjarne Tove		Elsa	Liv	HK	Skjalg	Cecilie	Anne	TOTAL
								508				
	X	X	X	X	X	X	X	X	X	X	X	11
2		X	X	X	X	X	X		X	X	X	6
3	X	X	X	X	X	X	X	X		X	X	10
1		X	X	X	X	X	X		X	X	X	6
2	X	X	X	X	X	X	X	X	X	X	X	11
,	X	X	X	X	X	X	X	X	X	X	X	11
	X	X		X				X	X	X	X	10
3	X	X		X	X	X	X			X	X	8
	X	X	X		X							4
ľO	7	6	7	8	6	8	8	5	9	8	8	

Møller:

Rakel	l Heidi	Odd-Bjarne Tove	Tove	Elsa	Liv	Britt	Skjalg	Cecilie	Anne	TOTAL
X		X	X		X	X	X	X	X	8
X	X	X	X	X		X	X	X	X	10
X	X	X	X	X	X		X	X	X	10
X	X	X	X	X	X	X	X	X	X	11
X	X	X	X	X	X	X	X	X	X	11
X	X	X	X	X	X	X	X	X	X	11
		X	X		X		X			7
X	X	X	X	X	X	X	X	X	X	11
	9	8	8	9		9	8			



# 5 Phenomenological interpretation

The same empirical material as has been used above, is in the following analysed with the help of the EPP-method. I have chosen to present rather extensive quotations as examples of meaning units (MU) found about dominant themes. I have kept much of its context and the inner coherence since I wanted to be as close to the direct telling as possible in this presentation, which involves Step 2 in Karlsson's stepwise method. The formal results of all steps are discussed and analysed in Chapter: "Conclusions" and "Discussion".

#### **HOME SWEET HOME – ELSA**

#### ALL THAT I HAVE

Elsa brought two persons to the first interviews, one a member of staff from the ward where she was admitted together with her contact-person from the community. There were then four of us present at the first interview. Within three minutes, she told how she had had a hard environment when growing up. "A lot happened", as she put it. <sup>312</sup> She had moved a lot, primarily between her parents and her grandmother. She had had to be like a mother to her own mother and she had experienced much that a child should not have to experience. Her mother was not able to give her any feeling of security, was mean to her, called her things and abused her. Her mother had a serious psychiatric diagnosis, and Elsa had to take responsibility for everything at home, including her little sister.

My childhood wasn't good. Thought my mother was my little sister. 313

Her mother moved abroad without telling Elsa, and left the children in the care of their grandmother. Elsa started to get serious problems at the time of her first year in school and was admitted to several psychiatric hospitals and institutions around Norway, often

<sup>312</sup> Elsa 1:1

<sup>313</sup> Ibid., 1:6

far away from home. Several doctors prescribed medicines that it was not suitable to combine, which resulted in Elsa's feeling like a walking zombie, without any relief of her initial sufferings. When she wanted to reduce or stop taking the drugs her mother refused and forced her to take them, and this went on for several years.<sup>314</sup> She had no coherent memories from the time she was nine to twelve, and she says:

So it's a part of my childhood that I don't remember, it's just like I haven't lived. It is horrible. 315

#### I asked if the drugs had helped her at all:

No-o-o-o-o --- maybe I managed to concentrate better, I don't know. They wanted to give some new medicine because they thought I couldn't concentrate, but mother didn't feel any need to change my medicine when I was already doped completely. Very much doped. I was on so many drugs I could hardly walk. I suffered a long time. It was like hell.

I could walk but hardly lift my feet over the ground. That isn't nice. And I looked like a real shrew when I walked bent over with my arms hanging; I looked like a real shrew. Before that I was doped I was best in my class in sports, <sup>316</sup> for example. But it was so hard for me to run with all the medicine. — The only subjects I had in the end were handicraft and ceramics. <sup>317</sup>

She was given drugs for her problems with concentration that resulted in her not coping with any other subjects in school besides handicraft and ceramics, this despite the fact that she had been the best-performing student in all subjects prior to the drug treatment. She took care of the home, her sister and her mother during this time; she was nine years old at the start. It is revealed in the interview that even at the age of nine she had a hard time concentrating and she heard a lot of voices that ruled her thoughts and life. <sup>318</sup> Her mother was during this time living together with a violent man.

He, the first was bad, was violent to me, he drank and such things. Mother just stayed with him because he had a farm, and I had to work very hard. Everything was my fault, it was my fault, my fault, my, my my my. It wasn't the truth though but I was blamed for everything that went wrong at home. And he was psyching me --- So I was alone and had fixed myself and ... So I had a shower, and then he was standing there. My friend was there as well, I don't remember all that happened but he stood there. Then mother said: "You

<sup>314</sup> Elsa 1. This was confirmed by her contact person from the community that was present at the interview.

<sup>315</sup> Ibid., 1:4

<sup>&</sup>lt;sup>316</sup> She talks about running at this specific place in the interview but it became obvious in other parts of the interview that she was talking about other subjects as well.

<sup>317</sup> Elsa 2:5

<sup>318</sup> Ibid., 2:4

can't go in there, she's there" and then he ... he said ... and he went in anyway and looked at me naked, he stood there looking and laughing and smiled scornfully. <sup>319</sup>

It was not only the fact that her mother did not stop the man when he was entering Elsa's room disrespectfully, while her friend was visiting which made the situation even more awkward.

Elsa had been sexually abused and treated in a humiliating way several times and over long periods during her childhood. At one time when she refused to go back to her mother's place after a time at a psychiatric institution she was sent to her father in Northern Norway. She had a better time with her father until her uncle threatened to kill her and abused her sexually when her father was not present. Her uncle had abused her sexually before several times when she was at her father's during school holidays and so forth. Her uncle told scary stories to Elsa during her entire childhood about witches and sirens of the woods that her uncle had sex with and who would come and harm and kill her if she told anyone that he also forced her to engage in sexual acts. 320

On her first day at school she knew she would have a bad time and it was early in school she started to hear voices. When I asked why she knew she would have a bad time in school she answered:

I just knew it would be bad for me. Why I don't know. But I remember when I was in kindergarten some boys tried to strangle me and took my underwear off. I remember I had a friend that was in her 9th year of school. She tried to stop them. They didn't listen to her. Have always been afraid that they wouldn't listen. It was horrible. Because when I was young I had a problem with incontinence. And I had no pad then, this incontinence pad: so I had to wear wet pants. That wasn't nice. <sup>321</sup>

The situation was aggravated by the fact that she was incontinent for urine, and she did not get any help for that. She did not have any sanitary towels but had to have wet pants every day. In her medical record it is reported that she had her incontinence for urine, and later excrement, because of the sexual abuse she was exposed to.<sup>322</sup>

She had her first psychotic episode in school, an experience that of course left her with horrible memories. At one time she saw the sirens of the woods and witches her uncle had talked about at the pool when she was swimming with her classmates; she panicked

<sup>319</sup> Elsa 1:4ff

<sup>320</sup> Ibid., 1:3

<sup>321</sup> Ibid., 1:3

<sup>322</sup> Ibid., 1:3

and ran off and hid. Her classmates tried to calm her but thought she was strange when she said she heard sirens of the woods and witches talk to her.<sup>323</sup>

When she first understood that the voices were only in her head she kept it a secret for over a year for fear of anyone considering her a lunatic. She had no one to talk to at this time and she trusted no one.

But I remember that when I heard voices I kept it a secret a whole year, because I thought "My God, I'm going mad". I was petrified, I was petrified of myself.<sup>324</sup>

Elsa told about the time when she saw delusions for the first time:

It was just like there was a reincarnation, I didn't know what to believe, because my mother said she had seen him and ... But, when mother says she has seen him, I don't know, ... I saw him anyway. <sup>325</sup>

Her mother does not help, but instead confirms her delusions, but at the same time she is not sure if her mother really has seen the same things. 326

I ask her when the voices started and how she felt before the voices and the music came, but she could not answer that. She just calmly stated:

I don't know how it is to feel good. --- I don't know how it is. Probably I'm a B-type person. 327

She had no experience of feeling well, healthy and free from the voices, she did not even have any idea of how it could be without them – she tried a guess later in the interview but she did not know anything else than a negative definition of being ill; she tried: healthy must be like being free from schizophrenia, not hearing voices – but she just states that she does not know how that would be.<sup>328</sup>

It was frightening ... Yes it was ... It was terrible ... evil I couldn't find peace anywhere. 329

Elsa spoke about her ability to fly, 330 an ability she used when she felt worst. She said a little ironically that she had learnt that from a child psychologist, but it can be understood

<sup>323</sup> Elsa 1:3ff

<sup>324</sup> Ibid., 1:7

<sup>325</sup> Ibid., 1:5

<sup>326</sup> Ibid., 1:5

<sup>327</sup> Ibid., 1:8, 2:6

<sup>328</sup> Ibid., 1:8

<sup>329</sup> Ibid., 1:3

from the interviews later that she had believed herself to have that ability for almost her whole life, far earlier that her first contact with the psychologist. She described the technique as an ability to lift from her body and contemplate herself from the outside. She could then fly free in the room without her body and she then felt calm and secure. She was very aware of how she appeared to other people.

The voices were echoes of things her mother and uncle had told her when she was a young child, for example her mother had told her she was

evil, horrible, abominable, egoistic ... Then she says she wishes I would die ... -- that she hates me. I don't think she has any maternal love. She can't have, after all she's done. <sup>331</sup>

The hallucinations are a psychotic symptom, but I have included them in this interpretation since they are the first change Elsa identifies. In her telling there is no information about any time prior to the hallucinations but she describes the start as music, foreign music, soft and quiet, that at the beginning calmed her. The voices started to become stronger and stronger and she did everything not to reveal her experiences.

She said that the voices from the start were just voices she could argue with and discuss different situations with, but eventually they started to live their own life. From the beginning she experienced being in control of the voices but she lost that in time. Many things have been decided over her head and she has been diagnosed as having many different afflictions. She illustrated it like this:

And then they decided I had MBD. 332

She had no say at all and as if it did not have any reference to her. She had had very little say in her life, and she was very afraid that her little sister was suffering still living with their mother, and this remained a burden to her.

Elsa could at first not remember what her uncle looked like, however, even though she was well into her teens when he passed away, but she describes how she recognises the shadows she saw when she was feeling ill, in pictures of her uncle.<sup>333</sup>

She had felt alone all her life and had never had anyone to talk to, and she wished that the social authorities had placed her and her sister in foster care early so they maybe could have prevented some of the harder experiences.<sup>334</sup>

<sup>330</sup> Elsa 2:7ff

<sup>331</sup> Ibid., 2:2 passim

<sup>332</sup> Ibid., 1:5

<sup>333</sup> Ibid., 2:3

#### Part C

She has had a good relationship with her father. He did not know about the sexual abuse until she was thirteen years old. She had not dared to tell him, and when the abuse was discovered and the uncle had been found guilty in court the uncle was too old to get a penalty according to the law.<sup>335</sup> That was one year after the abuse had stopped!

# DARKNESS OF SILENCE<sup>336</sup> – TOVE

#### **ONLY ME**

This young woman tells a very detailed story about her experiences. The interviews with her were the longest and we talked for more than two hours at the first one. It was hard to stop her. She was worried that she would not be good enough. After the first interview she wondered if what she had told was OK, since she had been a bit absent-minded, and she wondered if I was wondering about anything she had said. She had been living in Sweden most of her life. Interview number two was mostly chaotic and what she said was not always coherent. I let her talk the way she wanted and I tried not to make her stop. I asked very few questions and I let her stream of feelings and information flow out of her. Her story is filled with abuse, chaos and treachery. Several family members have psychiatric diagnoses.

We have it in the family. My uncle, my mother's five sibling, as well as a niece and a nephew of hers, are all severely schizophrenic or manic depressive, severely manic depressive. They can't manage to do things.<sup>337</sup>

#### She spoke about her mother:

My mother is from Iraq and in Iraq you hit children to teach them right from wrong. She was also sick in a way ... she's on Cipramil today. But she's a kind of person that needs to do things all the time otherwise she starts thinking too much. But sometimes she would beat you with the vacuum cleaner just because you were at the wrong place. <sup>338</sup>

<sup>334</sup> Elsa 2:10, 2:12

<sup>335</sup> Ibid., 2:14

<sup>336</sup> Darkness of silence - Tove's expression of when nobody notices the obvious.

<sup>337</sup> Tove 1:11

<sup>338</sup> Ibid., 1:4

Her younger sister had wanted to die since the age of seven:

When my sister was seven she wanted to kill herself. She went and told everyone: "I want to die".

She had a brother that was aggressive and kicked and beat her when she did not understand something. Her brother had been bullied at school for being a foreigner. He had been called Fatso and that was what the mother called him at home. Her brother had several times "flipped out" and been on the point of killing his cousin, the most serious incident occurring when her brother was in Iraq to visit family members. Tove had been in Sweden at the time of the incident, and I asked about the cousin:

Yes, he wanted to kill him there. No, I don't know, we're a rather chaotic family. He has become a drug user, as revenge.<sup>340</sup>

Her brother had a lot of debts and Tove thought he was a drug dealer. She also spoke about her brother's upbringing. Their mother had become pregnant by accident through a man the family never accepted. The child, her brother, was taken away from her at the age of three months and was held locked in a house together with relatives of hers. He could see his father's house from the windows but was never allowed to meet him. When he was eleven or thirteen it is a bit unclear in the story – he was taken care of by his grandmother. The grandmother had cancer and would soon be unable to take care of him. An uncle took over the responsibility and let the child meet his mother. But her brother was brought up knowing that if he met his mother his relatives would kill him. When I asked why he was taken, it seems that it was as much for the reason that he was a boy and would work for them as for the reason that they did not accept his father. He was literally stolen and forbidden to meet his parents. Tove was unwanted by everyone, including her mother, and she understood it was because she was a girl.<sup>341</sup>

Her mother and her father argued a lot and Tove said that her mother had for example thrown knives at her father and tried to kill herself in front of the children. Tove had a different father than her brother as far as I understood.

Tove said that her brother had abused her sexually from when she was eleven to when she was nineteen. She feels like she has a huge snarl in her body and she tries to convince herself that she is angry with her brother but she does not always succeed in that. Her mother had refused to believe her when she spoke about the abuse, but instead told her

<sup>339</sup> Tove 1:4

<sup>340</sup> Ibid., 1:5

<sup>341</sup> Ibid., 1:5

#### Part C

what a disgusting and mean person she was to say such a thing. <sup>342</sup> She was still very afraid of her mother and brother:

Yes, I'm afraid of my brother ... he wanted to kill me. So did my mother ... she beat me with a spade and said she wanted to see me dead. That was because ... she started to talk about God and things. She has her statues, different ones to which she prays ... and then I went up the stairs ... There's a noise on those stairs. But then ooohhhh there's too much noise. My father was on a course or something because he wasn't there. And then she said I had no respect for God. But then I said I didn't believe in God, and then she took her statues and threw them around and said: "Are you satisfied now? Now I'm going to believe in the devil!" But I was so tired, I was going to leave very early in the morning for Idre because I had a scholarship to go there and I was already packed. So I took my bags, it was maybe three o'clock in the morning, in the middle of the night. I took my bags and left, I was going to stay at the bus stop waiting for the bus, for four hours. But she came after me and said: "You must come back" and she got this spade and had me sitting on my knees in the hallway and praying to God: "I'm sorry I don't believe in you", but I had to really mean it and then my brother came home and he just stood there eating a sandwich and watching like this maybe ... If this is the hallway [Tove shows]. At the same time he just stands there. He doesn't do a shit and then he leaves. And then this damn lamp. And then it's my brother. I wanted the money back. But he's always tired so he can't get the money and then I started to believe there was no money ... at all. And then he asks if I'm lying and he gets really pissed and we are in his flat. I don't really remember ... we argue a lot. Screamed at each other ... and then he says he has such an urge to kill me ... "I would like to kill you" and then he looks at me and says "yes yes" and he goes into the kitchen to find a screwdriver or whatever and I say "OK do it" and it looks like he's going to the kitchen but he doesn't, he is lying down. And fortunately my father comes. And then we pretend like nothing has happened. I just got home. After that I haven't seen or heard from him. 343

She could not stand the voice of her brother, nor his aroma. The brother is her mother's hero and there are pictures of him everywhere in their home. Her mother told her she had to love her brother. <sup>344</sup> Her mother also threatened her with risky men throughout her childhood. She says:

They thought I was pretty and then I started to cry because I thought I had to marry them ... have children and such. I thought it was really disgusting and scary ...  $^{345}$ 

#### She also said about her mother:

When you're a bit like this – paranoid – like when my mother had an roommate, when she had been drinking ... she accused him of being a pedophile, she was 100% sure ... the thing is, she has her ideas, theories and answers to things, and they are important, just that. Sometimes she would stand with a knife and wanted to

<sup>342</sup> Tove 1:11

<sup>343</sup> Ibid., 2:6f

<sup>344</sup> Ibid., 2:7

<sup>345</sup> Ibid., 1:10

kill her and hers ... I don't know... But she always said it was because "you don't like me and no one likes me, you hate me". And then it didn't matter that we tried to convince her that we actually cared about her. But it isn't that easy to like someone like that, but you couldn't say, could you?<sup>346</sup>

First I haven't had my mother then. She hasn't been the mother every child needs. A mother that comforts you when you cry... Because at our house you are not allowed ... when I was little then ... a child is not supposed to hear from her mother that oh my you are walking horribly. You are doing this and that you are eating wrong and ... I wish I hadn't given birth to you ... <sup>347</sup>

When she cried as a child her mother thought she was cheeky, and she said that if she walked too hard on the floor she was beaten.<sup>348</sup> She was confused and forgot to eat during long periods. The year prior to the admission she weighed 38 kilo. She had not noticed that she had lost weight and discovered it by chance in a shop where she weighed herself for fun.<sup>349</sup>

No, I have this growl in me ... I'm angry. And then I try to think about what makes me angry, and the only thing I can think of is that I'm angry with myself, I hate myself, I'm really pissed with myself, I don't at all like to be me. I don't like it at all. I feel so problematic.<sup>350</sup>

She told of how often she had been afraid that she would commit suicide and it seemed like she was fixed on thoughts about death when she was feeling ill, she wanted to die at the same time as she was really afraid of dying.<sup>351</sup>

She spoke about her "woodpecker thoughts", thoughts about things she regretted or things that had happened long time ago that she could not let go of. <sup>352</sup> As an example, she had a nightmare about her boyfriend being unfaithful in front of her eyes, an image feeling she could not let go of.

So I tried to control my thoughts but it was only a dream and it has nothing to do with reality that you turn so strange when you don't think you have any friends. You are brooding and insecure if it's like that. You just become that way. 353

She talked about her sleeping disturbances:

<sup>&</sup>lt;sup>346</sup> Tove 1:10f

<sup>347</sup> Ibid., 2:4

<sup>348</sup> Ibid., 1:9

<sup>&</sup>lt;sup>349</sup> Ibid., 2:5

<sup>350</sup> Ibid., 1:13

<sup>351</sup> Ibid., 2:2ff

<sup>352</sup> Ibid., 1:1

<sup>353</sup> Ibid., 1:3

And when I don't sleep I think, and the thoughts are like ... like you feel lost and frustrated. You go through agony and then I can do nothing at all. I don't know, you just feel so failed in a way, can't do anything. Totally failed in a way... you can't do anything... or maybe I can do this or we can do like this... feels like no, it has to wait. Have no feeling for it... Lose the urge... And then I eat... No I don't know, maybe I eat poorly and it is hard to concentrate... I get the feeling that I'm lost, restless, nothing matters. Don't want anything. I don't want to meet people... I just stay at home, and all I want is to sleep... I don't know... the first thing is that I want to sleep; I can't manage ordinary things... 354

During the interview she spontaneously started to think about how it is to be normal and feel good:

It is... I don't know what it is to be normal... I don't know... Everyone has something... nobody is always good... everyone has their problems... it comes to everyone... Before I thought that well, when my problems are solved, then... And then they came again. 355

Get up in the morning; make breakfast, to do what I should, maybe walk a bit. I want to learn. <sup>356</sup>

# THE CRASH - ODD-BJARNE

#### WHY ME?

This young man had been in several accidents and it seemed like he did not have a functioning relation with public authorities. He told of a big car accident, a head-on accident, and after that he had been in other accidents at least five times riding his motorcycle.

He was very tired when I met him the first time. He came to the meeting place early in the morning even though our appointment was for late in the afternoon. I had to wake him up when we were to start. He was tired but I had the feeling he was proud of being in this study as someone took him seriously and let him tell his whole story. He did not allow eye contact at the beginning of the first interview. He asked for a smoking break after about 20 minutes and after that he lightened up a lot. He showed me pictures of his car that he was reconstructing, and he helped me willingly with the tape recorder when we started again after the break. At interview number two he was significantly more open-

<sup>354</sup> Tove 1:1

<sup>355</sup> Ibid., 1:9

<sup>356</sup> Ibid., 1:9

minded and accommodating the further the interview went on. He even starting to tell secrets about illegal things he did or had done. He said after the first interview that he would be more into talking next time.<sup>357</sup> He seemed shy and a bit nervous but friendly and cooperative.

He spoke about the accident and he thought it unfair that he had not recieved any insurance compensation. He was injured and had to stay two days in hospital. He experienced it as hard to take that he still had glass splinters in his face, under his skin, that ached and irritated him a lot.<sup>358</sup>

He said that the other driver had bumped into him, and then he draws a sketch of the accident to explain to me it seemed to be head-on. The other car was on his side of the road and he was not able to drive closer to the kerb since there was a large stone. There were obscurities about the accident. I asked if he had hurt himself badly in the other accidents and he misunderstood me as asking if he wanted to get hurt.<sup>359</sup> When I kept asking if he wanted to be in another accident, since I did not understand what he meant at the beginning, he explained:

To fall over the handlebars? The thing is if I buy a new moped, and it happens, it'll cost the state 25000 to run me over every time, so that's really great, because then I've a brand new bike with the most expensive insurance and the law on my side, and then it's my turn to be lucky.  $^{360}$ 

During the last interview he used a lot more gestures, which of course are not shown on the recordings, and he became more and more involved the more we talked. He described himself and his "attacks", the so-called epileptic attacks.<sup>361</sup> It was hard, though, to understand what kind of attacks they were, and he had a very hard time explaining them to me. At first I thought he was talking about migraine, or herpes, but later epilepsy. He described it as chains hitting his back.<sup>362</sup> I asked why he had got in touch with a psychiatric clinic and he thought it was because nobody had asked him how he was after the accident, not physically or mentally.

I was just sutured and sent home... 363

<sup>357</sup> Odd-Bjarne 1: after the setting

<sup>358</sup> Ibid., 1:2; 2:5

<sup>359</sup> Ibid., 1:5

<sup>360</sup> Ibid., 1:5

<sup>361</sup> Ibid 2:6ff

<sup>&</sup>lt;sup>362</sup> Ibid., 2: introduction. The attacks were psychiatrically examined without revealing any organic cause.

<sup>363</sup> Odd-Bjarne 1:9

#### Part C

#### But later he revealed:

Yes, it was through a psychiatric ward, well I was there because I was in hospital after a ... happened, tried to kill myself, but that is nothing to be proud of: $^{364}$ 

It was also obvious in the interview that he had tried to commit suicide and that he did not have the best of times even prior to the accident. He did not want to talk about the suicide attempt, but he said it had started with his girlfriend's leaving him for another boy. He also said he had not been able to handle life as well after the accident as before. He did not really want to tell any details:

No, it was my ex-girlfriend and also that I didn't think anyone would believe me if I tried to talk about it. And the reason that I talk about it today is that I'm pissed about being made to work and everything goes to hell, when I know I should have disablement pension. And if there's something about me that makes people believe something else, then I just have to come through and tell how it is ... Because I've been like this for 4 years thinking and wondering, and I know how hard it has been ... 365

He felt misunderstood and now the only thing he wanted was to be considered disabled and get a disability pension. He felt like he was wrong in some way and he was in desperate need of somebody to understand him and listen to him. I asked him to tell me a bit about his family:

Mother, father and my sister and me, everyone is a wacko, but I don't know, I can't fucking explain, I would have to sit here for 25 years...<sup>366</sup>

In the later interview I asked him more about himself but he had a hard time talking about himself. He did not know what to tell. He suddenly said that he had accidentally walked in on his parents when they were making his little sister. He thought of that as very hard, otherwise he had a good childhood, he said. He had been the only child for a very long time, his sister was ten years younger, and he had got almost everything he wanted. Then he changed the subject again and started to talk about his motorcycle. We got back to the accident several times and how he felt guilty, and he tried to convince me that he had done 100% the right thing. He wanted compensation for the accident, he thought he had lost four years of working ability, and he wanted compensation for that. He wanted to explain his "attacks" and started with:

<sup>364</sup> Odd-Bjarne 1:10

<sup>&</sup>lt;sup>365</sup> Ibid., 1:10

<sup>366</sup> Ibid., 1:11

Well I now know that I'm ... What is it called ... I think I forgot to tell you last time too ... Every time I'm going to say it I just want to say herpes, but that isn't right ... I''

He thinks of epilepsy again, but it is not likely that it is epilepsy that he means. All the time thought I associated with migraine but he was not satisfied with that either.

Well, it was like there was something strange, but I can't find a word for it. 368

He felt weird and confused and continued:

It could be something physical that I have in my head and it could be something psychological that I have, I don't know... I'm so unsure... No, everything is just gone. I don't know how to explain... $^{369}$ 

He seemed confused when telling about these phenomena, sometimes it was shakings, sometimes chains hitting his back, sometimes he wanted to sleep and sometimes he spoke as if he had claustrophobia.

#### THE INVISIBLE CHILD - LIV

#### MOTHER?

Liv has a history characterized by a problematic relationship with psychiatric personnel. It was necessary to meet her on her conditions. We met at an official place and without my recording the interviews.

At the time of the interviews she was having a very distressing time. Her husband, a refugee from Turkey, could not get a residence permit even though they had been married for several years and even had a child together. The child was placed in foster care at the age of three months and Liv could only meet her son a couple of hours every eight weeks. The son was taken away since Liv was not seen as able to connect with him properly. While Liv was pregnant she was treated by force, which included heavy medication even though she asked not to get medication that could harm her baby. She also got the diag-

<sup>367</sup> Odd-Bjarne 2:5 f

<sup>368</sup> Ibid., 2:5

<sup>369</sup> Ibid., 2:7

nosis of schizophrenia during this period, in the midst of threats from her psychiatrist as she experienced it. The psychiatrist said that until she agreed with the diagnosis she would be kept in by force. The only thing she wanted was to get out of the hospital and take care of her pregnancy, so she agreed with the diagnosis. The diagnosis of schizophrenia has later been used against her in her attempt to get back custody of her son or at least be able to meet her son more often.

During her childhood her parents got divorced and she moved to Northern Norway with her mother. She described that time as depressing since she had to leave all adults she had faith in. She had no traumatic experience of the separation from her father, since she experienced him as absent during childhood. In Northern Norway she started to get problems socially, she was mostly occupied with the difficulties with her son, though it became obvious when reading her medical record that she had been sexually abused during long periods both during childhood and adulthood, primarily by her grandfather and later, by a boyfriend. The grandfather had lived with her and her mother during most of her childhood. At last the abuse was revealed and the man was taken into court. He then committed suicide and her mother blamed everything on Liv. Later Liv met a man with whom she fell in love but he was a known sexual abuser and used Liv in every possible way until she collapsed mentally. Liv's mother and the boyfriend competed in taking control of her life and her medicines and which medicines she had to take. Often her drugs were used by the mother and boyfriend. In many cases it seems like Liv's mother told different doctors about her daughter's disabilities and inabilities and got the doctors to prescribe medicines that her mother then used herself.

The culmination was when Liv was 17 years old and started at a new school. She felt that she was bullied by the teacher. She was seriously ill and admitted to the hospital. The teacher made an agreement with the doctor to handle Liv's medicines, which resulted in the teacher having total control over her life. The teacher was misusing her power in many ways and forced Liv to take her medicines in front of her classmates. All this information has been confirmed by psychiatric personnel.

At one time when she was ill she was admitted to a treatment centre near where she lived. She tried to tell of her problems and sufferings and ask for help but no one listened. Eventually she was given such strong psychopharmacological drugs that she became unconscious, and then they sent her by helicopter to a locked in-patient clinic, without informing her about what was happening. Nobody she knew went with her in the helicopter and she woke up during the flight not knowing where she was and then told herself:

So I must have been taken by UFOs. 370

This was later, in her mind used against her in diagnosing her as schizophrenic. The story of her life included so many awful situations and incidents, no single one of which a lonely child should be expected to bear. Besides all abuses, her mother and grandfather were using alcohol heavily, which made Liv's childhood really insecure and violent. One time the mother and grandfather were drinking so heavily they fell asleep while the house was on fire. They blamed her for the fire.

It was confirmed by her medical record that doctors disagreed about the forced treatment, both times.

## **MY RELATIVES - SKJALG**

#### MY SHADOWS

This man had asked for help at the child psychiatric clinic since he had a drinking problem. When he was in his early teens, he had moved to a large village when he started upper secondary school. Before that, he had been living with his mother (his parents were divorced) and been well-functioning in school. His father had left them when Skjalg was newly born and his mother had not had any new man after that.

During the time he was growing up he was sexually abused by a relative living close by, regularly and over a long period. This was also one of the few men in his close family. This man used several relatives sexually. Skjalg told of his difficulty in finding someone to talk to and to trust and of how memories and flashbacks from the abuse started coming back when he was fifteen. After that he started to drink more and more and eventually everything just went to pieces for him, he could not stand his memories any more, but still had difficulty finding someone to talk to. He started to hear voices and see things. At the beginning he just thought people were talking about him behind his back, but this started to appear also when he was alone in the woods or at sea. When he tried to follow the voices he found no one. He experienced sleeping disturbances since he believed there were people talking about him outside his window at night. The phenomena increased

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<sup>370</sup> Liv 1

#### Part C

and at the end they were regular hallucinations and he was admitted to hospital, could not handle school.<sup>371</sup>

It was when I was ... It was the summer, it was like the summer of 2001, it was just like a lot of memories, a lot of thoughts, came back and it was then it started ...<sup>372</sup>

I was worried that I would tear the house down with all my thoughts and everything would break. I saw spiders and shadows everywhere. 313 ... It was like seeing something invisible/... /I just felt it 314

He says himself that everything is flashbacks from old experiences. When I asked about the voices he explained:

It was much the same thought that I had. 375

I think maybe I have come to that way of thinking is because there's been too much negative. --- Because I was abused as a little, little boy. <sup>376</sup>

When the visions and voices were unbearable he was admitted to hospital, where he was medically treated for his symptoms:

And then everything disappeared. And everything turned very quiet up in my head. It was almost a loss in the beginning, because I was used to all the noise and talk and suddenly everything was dead.<sup>377</sup>

He once in the interview said he missed his thoughts in one way, because when he took his medicine he did not have any fantasies at all and it felt more like that other people's thoughts just passed him. He was afraid that people would see him as dumb and lazy.<sup>378</sup>

He had a hard time talking about the abuse and he had not told anyone until he was admitted to hospital with psychotic symptoms when he was well into his teens. All this could happen even though many of the doctors and therapist, knew there was a man in this village that sexually abused several children.

<sup>371</sup> Skjalg first interview

<sup>372</sup> Ibid., 1:8

<sup>373</sup> Ibid., 1:7

<sup>374</sup> Ibid., 1:7

<sup>&</sup>lt;sup>375</sup> Ibid., 1:4

<sup>376</sup> Ibid., 1:2; 1:8

<sup>377</sup> Ibid., 1:6

<sup>378</sup> Ibid., 1:10

#### CONCLUSION

This group is heterogeneous, some patients being clearly characterized by their history and their way of telling about themselves and relating to the experiences. Some of the patients seem used to reeling off their history without many feelings or reflections; they did not care anymore if people get hold of details of their inner sufferings or difficulties. Many stories were almost unbearable to hear or to read about in the medical records. This does not in any way mean that any of these patients were reluctant to talk about what had happened. On the contrary it was striking that all these patients with trauma revealed their trauma within the first minutes of the interview. Those that were most used to talking about their trauma were also those who had the most marked psychiatric language, as if they were in a way reeling off a piece of homework which they knew by heart. It was obvious that they had been talking a lot about their problems as a part of their treatment. All this reeling off was separated from their actual self during the telling. Their real self was uncovered in other, less detailed parts of the interviews. Some

Others that had not had contact with psychiatry for as long were more hesitant in talking about intimate details. They seemed more puzzled, and struggled more in defining and telling of their sufferings. Again this does not mean that they did not have a clear opinion about why their sufferings had started. Every patient with a trauma was convinced that their trauma had started their sufferings and changes and without it their life would have been different. The patients that had less contact with psychiatry talked in much more positive terms about themselves, as if the sufferings had not taken over their entire self. They could speak about parts of their personality that actually were positive but sometimes difficult, like Tove's happiness, Heidi's caring sides and worrying, Odd-Bjarne's interest in cars, Britt's fantasies and mysticism. Things that other people could experience as difficult, or that they thought other people experienced as difficult.

An obvious question emerges: were there other relevant themes discussed by the informants, themes that in one way or the other could be relevant for the understanding of their mental state? And yes, of course the informants talked about a lot of other things, apart from the abuse, both things and experiences that did not relate to the abuse, such as that nearly everyone spontaneously talked about what it means to be "healthy" and "ill". Some of them did not even have a clue as to what it actually meant to be healthy: they said things like "it must be not being ill!" or just being rid of the suffering. Elsa said that

<sup>&</sup>lt;sup>379</sup> It is not necessarily a question of details of sexual abuse or violence, it may instead concern situations related to health care situations.

<sup>380</sup> For example: Elsa

she had *no idea* what it meant to be healthy or even feeling well. These negative definitions of health could reveal an almost lifelong suffering from these patients, some could not even recall "a time before" the problem. Odd-Bjarne and Tove also considered themselves as always being B-type people, maybe not always as apparent as during the time of the interviews.

Another theme that was discussed in the interviews was the contact with psychiatric health services and authorities. Liv for example talked about her relationship with psychiatric personnel and how it had affected her. She did not understand how she could have got the diagnosis schizophrenia and why she was not allowed to care for her child. Bente, Liv, Elsa and Tove described the difficulty talking about the experiences that they had had and a theme in their stories was loneliness. In the stories severe and long-lasting loneliness was revealed. In the interviews I also got many details of how effects of the sufferings made it difficult to cope with situations. Elsa talked about the incontinence she got from the abuse and how helpless and stigmatized she felt. Odd-Bjarne talked about the physical problems and difficulties he had and how extremely hard he felt it to be to get others to understand his difficulties.

Were there, then, other known facts, for instance known heredity or somatic diseases that could help to explain their mental state? In every case the patients had been somatically examined and evaluated by doctors and no medical states, nor heredity factors, were discussed as a contributory cause of the patients' mental condition. Thus, except for the extreme traumas it is very difficult to find elements in their lives that contributed to the understanding of their prodrome-like phenomena.

Many stories were very hard to listen to, containing as they did, information about sexual abuse, violence, absent parents and extreme loneliness not to mention all physical problems and disabilities that were the result of sexual abuse and violence, and some disabilities had even turned chronic.<sup>381</sup> Many of these disabilities had the effect that the patients over and over again had to expose their inner and most embarrassing problems and disabilities to health-care personnel (see the part on revictimization in Chapter 7). I have for ethical reasons chosen not to reveal all the details from the medical examinations and concrete information about medical statements, and the details would not have benefited the analysis.

<sup>381</sup> For example: Tove, Britt, Liv and Skjalg

# PART D – CONCLUSIONS AND DI-SCUSSION



# 6 CONCLUSIONS

## CONCLUSIONS DERIVING FROM THE PRODROMAL INTERPRETATION

The original aim of this study was:

1 – To see if it was possible to identify prodrome-like phenomena prior to a first episode of psychosis.

To try this question I allowed myself to apply two lists of prodromes on the empirical material. I did an analysis and found that all the patients had experienced prodromes, or prodrome-like phenomena, matching those described by Paul Møller and by Jane Edwards and Patrick McGorry. It showed that the patients had experiences similar to almost all the prodromes described, the following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the prodrome-like phenomena found: he following list gives an overview of the

<sup>&</sup>lt;sup>382</sup> Møller 2000, Edwards & McGorry 2002

<sup>&</sup>lt;sup>383</sup> This overview is based on information from interviews mainly but also completed with information from the medical records and has been checked by my supervisor professor Lisbet Palmgren who is a psychiatrist specializing in patients with schizophrenia.

Edwards & McGorry:

	Bente	Rakel	Heidi	Odd-Bjarne Tove		Elsa	Liv	Britt	Skjalg	Cecilie	Anne	TOTAL
1	X	X	X		X	X	X	X			X	11
2		X	X		X	X			X		X	)
3	X	X	X		X	X		X			X	10
4		X	X		X	X					X	6
5	X	X			X	X	X			X	X	11
5	X	X	X								X	11
	X	X						X	X			10
8	X	X		X		X	X			X	X	8
6	X	X	X		X							4
TOTAL	7	6		8	6	8	8	5	9	8	8	

Møller:

	Bente	Rakel	Heidi	Odd-Bjarne Tove		Elsa	Liv	Britt	Skjalg	Cecilie	Anne	TOTAL
1		X		X	X		X	X	X	X	X	8
2	X	X	X	X	X	X		X	X	X	X	10
3	X	X	X	X	X	X	X		X	X	X	10
4	X	X	X	X	X	X	X	X	X	X	X	11
5	X	X	X	X	X	X	X	X	X	X	X	11
9	X	X	X	X	X	X	X	X	X	X	X	11
7	X			X	X		X		X			7
8	X	X	X	X	X	X	X	X	X	X	X	11
TOTAL	7		9	8	8	9		9	~		7	

As shown in the above tables, all eleven informants had experienced phenomena corresponding with the analysed concepts of prodromes of psychosis. The patients had experienced the phenomena for various lengths of time – from a few months up to almost their whole lives.

I would like to emphasize that I did not wait for a diagnosed psychotic episode but deliberately chose to *interview* some of the patients before a diagnosis including psychotic symptoms had been made. This means when they were still being examined with regard to a possible psychosis, i.e. in a theoretically prodromal phase of psychosis. In some other cases the patients had recently got a diagnosis including psychotic symptoms. This method was chosen because I wanted to evaluate whether prodrome-like phenomena existed, and if they did, how they could be understood. I wanted to interview the patients as close to a potential prodromal phase as possible.

#### **DIAGNOSES**

As shown in the next table, seven patients received the ICD-10 diagnosis F. 20 – paranoid schizophrenia. Two more patients received, and a third one later received, the diagnosis Post Traumatic Stress Disorder (PTSD). Two of these patients also had psychotic symptoms. Another patient had the diagnosis bipolar disorder, and one patient stopped coming to the centre so I could not get any updated information in the follow-up, but she had psychotic symptoms at the time of the interviews. To summarize: by the end of this study ten out of eleven patients had been diagnosed as having psychotic symptoms and seven as having schizophrenia. And moreover, I interviewed many of these patients prior to an established diagnosis including psychotic symptoms or schizophrenia, i.e. in a period that theoretically corresponded with what in the literature is designated a prodromal phase of psychosis. Sec. 10 paranoid support of the patients and prodromal phase of psychosis. Sec. 10 paranoid support of the patients are paranoid support of the patients and prodromal phase of psychosis. Sec. 10 paranoid served paranoid support of the patients are patients are paranoid support of the patients are paranoid support of the patients are paranoid support of the patients are patient

<sup>&</sup>lt;sup>384</sup> One of the ten was only experiencing symptoms at the time of the interview whereas the other nine eventually received a diagnosis including psychotic symptoms.

<sup>385</sup> I have included both tentative and established diagnoses in the table.

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	Diagnostic status	Diagnostic status
	at the time of the interviews	2007
	Prodromal phase of psychosis?	Unstable personality disorder
BENTE	F32.3 Severe depressive episode with psychotic symptoms	AD/HD
RAKEL	F 31.5 Bipolar affective disorder, current episode severe depression with psychotic symptoms	Committed suicide 2005 F 31.5 Bipolar affective disorder, current episode severe depression with psychotic symptoms
	F43.1 PTSD	P 76 Anxiety and depressive disorder
HEIDI	F 41.1 Generalized anxiety disorder	F 41.1 Generalized anxiety disorder
THEND	Prodromal phase of psychosis?	F 42.2 Mixed obsessional thoughts and acts
ODD- BJARNE	Prodromal phase of psychosis?	F 20 Paranoid schizophrenia
	Prodromal phase of psychosis?	Prodromal phase of psychosis?
TOVE	F 32.3 Severe depressive episode with psychotic symptoms	
	F 43.2 Adjustment disorders	No new information
	F 20 Paranoid schizophrenia?	
	F 06.7 Mild cognitive disorder	
	F 06.5 Organic dissociative disorder	
ELSA	F 43.1 PTSD	F 20 Paranoid schizophrenia
	F 92.9 Emotionally disturbed childhood	
	F 88 Other developmental disturbances	
	F 99 unknown IQ	
	Axis V 1.0	
	Axis VI Moderate social disturbance	
LIV	Schizophrenia?	F 20 Paranoid schizophrenia
DDITT	D 1 : 2	F 22 Paranoid psychosis
BRITT	Psychosis?	F 43.1 PTSD
SKJALG	Recently diagnosed as having schizophrenia.	F 20 Paranoid schizophrenia
CECILIE	Prodromal phase of schizophrenia?	F 20 Paranoid schizophrenia
	F 43.1 PTSD	F 20 Paranoid schizophrenia
ANNE	Schizophrenia?	F 43.1 PTSD
		Non-organic psychosis

### CONCLUSIONS DERIVING FROM THE PHENOMENOLOGICAL

#### INTERPRETATION

My second aim in this investigation was to answer the question:

## 2. – How are these phenomena experienced and interpreted by the patient?

Ten out of eleven patients had experienced different forms of trauma. In eight cases extremely serious sexual abuse had been reported, and in the ninth case the personnel at the unit believed there was a history of sexual abuse in childhood. These ten patients had also experienced other traumata. In seven cases the patient had been abused by a close relative as an infant or up to preschool age. In the eighth case there was a situation with paedo-philia/prostitution for several years when the patient was in her early teens. One other patient had been abused as an adult by a man with whom she had a brief relationship and another had suffered a physical head trauma. Ten out of eleven patients could clearly describe what they believed to be a relationship between the trauma and the changed experiences, i.e. the prodrome-like phenomena. Only one patient did not have an understanding or explanation of the phenomena or of the psychosis she eventually got.

During the interviews it became obvious that the sufferings, difficulties and changed experiences that these informants were talking about contained a lot of phenomenological and coherent information that the informants believed to be important. These phenomena were often related to the experienced trauma, said the patients, and the changes described were understandable to them. They mostly explained the phenomena as reactions to early experiences and these had developed into something unbearable, like a constant feeling of fear, or voices telling them bad things when they thought they were alone, fear of close relationships, loneliness, low self-esteem and so forth.

These prodrome-like phenomena were also presented by the patients as being changes in an ongoing process. It proved important to analyse these phenomena within a coherent analysis of the patients' life-world. They have therefore focused on their complete life-situation. A significant fact is that the traumata described were all so severe that I see no reason to discuss the differences between them. My discussion will focus on different risks and possibilities with regard to neglecting contra including phenomenological information, both in encountering and in treating the patient.

#### REVIEW OF TRAUMATA THAT THESE PATIENTS HAD BEEN EXPOSED TO

It is to be noted that some of these traumata were confirmed in the medical journals.

BENTE	Repeated sexual abuse in childhood. Prostitution as a child.	
RAKEL	Repeated sexual abuse by several family members during childhood.	
	Raped in her teens.	
HEIDI	Lost her friend to cancer, sexually abused by father (?), lack of moral	
	boundaries in the family. Unsure information.	
ODD-	Car accident with head injury.	
BJARNE		
TOVE	Repeated sexual abuse by family member in childhood and teens.	
	Lived under threat of being killed by her family.	
ELSA	Repeated sexual abuse by family member in childhood.	
LIV	Repeated sexual abuse by family member in childhood and cold at-	
	mosphere in which to grow up.	
BRITT	Drugged and raped prior to prodromal phase.	
SKJALG	Repeated sexual abuse by family member in childhood.	
CECILIE	No reported trauma.	
ANNE	Repeated sexual abuse by family member in childhood.	

A fundamental aspect emerging from these interviews is that the sexual abuse was perceived by these patients to be necessary for developing a psychotic illness: no sexual abuse, no illness. These abuses were also so fundamentally in focus for these patients that even if a detail or two should show not to be true, everything was considered as experienced.

#### **TOWARDS A CAUSAL EXPLANATION**

So, I have noted above that ten out of eleven patients strongly believed that their suffering (including their prodrome-like symptoms) was (partially) caused by their early traumatic experiences. It is therefore now natural to turn to aim 3 of my investigation, namely to seek an answer to the following question:

# 3. – What causal explanation of these phenomena can be given?

I will in the following consider the hypothesis that the suffering (including the prodrome-like symptoms) of these patients was *in fact* partially caused by their early experiences. I propose that there is a relationship between the abuse (the cause) and the later feeling of guilt, agony, despair, etc and thereafter psychosis (the effect). My hypothesis is not inconsistent with genetic or other bio-physiological theories, and there was probably some degree of predisposition for psychotic experiences among the patients in this study. My point is not to put different hypotheses in sharp conflict with each other but instead to show the importance of a more inclusive understanding.

During the interviews it became evident that the informants had all had a very severe and abusive childhood, and they were almost all in agree that their suffering was partially an effect of experiences in childhood. Consider for example Skjalg's comment at the start of the interview:

Well, I have my childhood. /.../Because I was sexually abused as a little little boy. 386

Or Elsa's comment as the start of her interview:

.. and I have not had a very good childhood. Many things happened. 387

She later spoke about her mother's inability to care for her and a sexually abusive uncle and so forth. Tove told many horrible stories of how she had been beaten and abused and neglected by her mother and brother.

My dad always tried to care for us when my mother beat us. I have always felt lost, they say it is an identity crisis because I am from another culture. But I feel very adaptive. ... Maybe it is not strange that I am the way I am ... maybe ... first I have had a mother. That maybe has not been the mother all children need. A mother

<sup>386</sup> Skjalg 1:2

<sup>&</sup>lt;sup>387</sup> Elsa 1:1

#### Part D

that cares for you when you are sad. ... Because at my home you were not allowed to ... A child should not have to hear her mother say: you eat wrong, you talk badly, I wish I had not given birth to you.<sup>388</sup>

She was abused by her brother and when she told her mother she was not believed. Similar things were told by many informants. Much of the suffering told was also very closely connected to the abusive situations during childhood. And many of the sufferings were described as emotional reactions to, and effects of, the earlier abuse. Several said that they heard the voice of the abuser or heard voices talking to them saying bad things. Or they spoke of the constant fear, a fear that no one would listen – both Tove and Elsa for example were preoccupied with a fear and hopelessness because no one had listened to them.

I will now argue for my hypothesis by putting the results of this study in the context of a psychodynamic trauma theory.

<sup>&</sup>lt;sup>388</sup> Tove 1:ff, 1:4

# 7 Discussion

# RETROSPECTIVE COHERENCY INSTEAD OF PROSPECTIVE SCHIZO-PHRENIA

I have chosen to exemplify psychodynamic theory with theory of the self.

Stern is an American psychiatrist engaged in research on infant development and he is one of the two leading theorists on the psychology of the self, the other being Heinz Kohut. More than Kohut, Stern has focused on the infant and the special circumstances that interfere with the infant's development into an adult and well-functioning human being. The psychology of the self is a part of the psychodynamic field of psychology and an extension and improvement of the early psychoanalytical theories introduced by Sigmund Freud and Carl Jung. Consequently Stern's theories, presented for example in his book *The Interpersonal World of the Infant*, are based on early psychoanalytical theories revised and combined with developmental theories.<sup>389</sup> Since many of the patients included in this thesis were abused early in life, some as early as infancy, Stern's theories were an evident choice.

Stern is used as an example but all psychodynamic theories show the relationship between early trauma and the infant's and child's psychological development. Children who do not get nurtured in the different developmental phases, or as Stern calls them senses of a developing self, simply do not develop the specific senses and abilities, or the senses and abilities are developed with dysfunctional elements.<sup>390</sup> The theories of the self are included in most contemporary forms of psychodynamic theories.

The patients in this study that had been abused had been so from very early years. It is theoretically possible that many of their developmental senses and functions then have been affected.

The theory of the self makes it vital to understand infant and childhood experiences. Every experience in these early-developed layers of the sense of self is continuous with the self and affects the self and the personality organisation throughout life. Difficulties as

<sup>389</sup> Stern 2004

<sup>390</sup> Ibid., pp. xxv

well as capacities are formed during these periods.<sup>391</sup> That also includes the ability to deal with and process negative experiences, developed with the verbal self.<sup>392</sup>

Using Stern's theories can shed light on many of the different phenomena described by the patients in this study. Several of the patients had in addition had an extremely dysfunctional family situation with no or very few objects to relate to, i.e. develop in relation to. Several had mothers who were either severely mentally ill or had severe problems with regard to relating to, and protecting, their children. It would affect these patients' abilities to develop all the elements of Stern's developmental senses. That would include the ability to relate to the self's perception, cognition and remembering while developing the emerging self from the time of birth. 393 This is, in Stern's theory, accompanied by the ability to feel and understand internal sensations. In this phase the infant also develops the ability to identify and feel it's first, emerging, sense of a physical self and later the core self. 394 This will make the abuses during this phase even harder to manage, not only because the self has little or no ability to understand, identify and describe the inner sensations and effects of the abuse, but also because the experiences are very hard to express to others. This specific ability is developed in the narrative sense of self.<sup>395</sup> Psychodynamic treatment in particular but also psychiatric treatment in general depends on the patient's ability to express and define his or her problems, and if that ability is limited this will of course become problematic and a source of complications in all contact with helping institutions and in communicating with others, like health-care personnel. Also the ability to define and separate oneself from external objects is affected if these phases are not nourished or are disturbed. This can lead to inability to understand the difference between one's own and others' needs, feelings and drives, which in the next step can lead to difficulty with regard to respecting one's own self and one's owns needs, feelings and drives. For example it could be a contributing factor with regard to why many abused men and women often continue to live in abusing relationships later in life. It is a question not only of the inability to respect and separate one's own needs, feelings and drives, but also the lack of functional and respectful representations. If you have not learnt what a respectful and nourishing relation could be like, and feel like you will most probably live the way you have learnt, as your only option. This is also significant in the discussion about freedom of choice: it is often said that abused men and women have chosen to live in such relationships. But the freedom of choice, interpreted in an existential way, demands at least

<sup>391</sup> Stern 2004, pp. 3-12, 26-34

<sup>392</sup> Ibid., pp. 162-182

<sup>&</sup>lt;sup>393</sup> Ibid., p. 37-68

<sup>&</sup>lt;sup>394</sup> Ibid., p. 69-123

<sup>&</sup>lt;sup>395</sup> Ibid., p. 174

two alternatives. If you have never learnt or experienced anything else, you will not have the ability to choose. You will simply have no option.

It is also possible that the ability to relate to and understand one's own inner sensations is disturbed. Also important is the ability of verbalizing one's own experiences, and this ability develops during the development of the sense of self versus others in combination with the verbal development, the feeling of self-coherence and the ability to identify and relate to one's self-history.<sup>396</sup> All the different senses would have been affected if the person had been abused so severely and consistently as in these cases. It probably would have affected the ability not only to structure one's own self as the core and essential form of an independent and functioning self, but also to relate to and manage the experiences in this and later developmental phases.

It is likely that all of these senses of self have been affected in the case of Elsa, Bente, Rakel, Heidi, Tove, Elsa, Liv, Skjalg and Anne.

So, the empirical material of this study suggests that the prodrome-like phenomena actually were partially caused by experiences early in life – experiences which the patient cannot now handle. It is likely, however, that many factors caused these phenomena. It is possible that some degree of predisposition existed among these patients that made them more susceptible. Regardless, I believe it to be essential in order to understand the illness that information about the patient's personal experiences be included and understood. Likewise in order to treat the illness partially caused by trauma it is vital to have information about the experienced trauma in focus, meaning that the trauma should be addressed as something beyond the individual's control. (Of course it is also vital to focus on many other aspects of the trauma.)

The changes were – as described in the phenomenological analysis – often changes in the patients' sense of reality, their suspiciousness, mental agony, concentration problems and so on – very much like prodromes described in the literature. For these patients it was obvious that the changes were dependent on early life events. The material is small, only eleven patients, and it is not a constant picture in early schizophrenia – but it represents a theoretical analysis *of how it could be*.

It is essential to acknowledge and discuss the information that lay in the changes in these patient's perceptions of the violation and abuse that they had experienced, since it could possibly have an effect on both prevention and prognosis, regardless of diagnosis. If there are different interpretations and these interpretations differ in content, target and aim, there is of course a question of precedence of interpretation. A biological, reductionistic, interpretation focusing on single clearly demarcated signs or symptoms could lead to

<sup>396</sup> Stern 2004, pp. 69, 91-94

a splitting<sup>397</sup> of the subject's self, in the clinical setting when presented to her or him, if the subject is convinced that the sufferings are at least partially caused by early stressors. This in turn could lead to the subject's (and in the future the therapist's) not understanding the coherency and the relation to earlier life-events that have shaped the personality organization.

#### SCHIZOPHRENIA AS AN ILLNESS CAUSED BY CHILDHOOD TRAUMA

Trauma, physical, sexual and psychological, has been shown to trigger many different psychological states – Post Traumatic Stress Disorder (PTSD), of course, but also depression, eating disorders and so on. Trauma has, however, more and more also been seen as related to schizophrenia.

I will in the following present current studies that show a relationship between child-hood trauma and later severe sufferings and illnesses.<sup>398</sup> It is a question of suffering that from a formally defined perspective corresponds to the definition of schizophrenia and other psychoses in DSM or ICD. The connection between abuse and psychological problems is known, and there need not to be any contradiction between a phenomenological and a biomedical interpretation of the prodromes.

Bertram Karon and Gary VandenBos write in their *Psychotherapy of schizophrenia: the treatment of choice* that already Sigmund Freud described how often sexual abuse and incest were part of hysteria.<sup>399</sup> Freud was certain that real experiences were often the triggering cause of hysteria. Freud also believed that these experiences were often mixed with other, more psychologically created memories which have often been misunderstood as solely fantasies of psychiatric patients with no relation to actual experiences.<sup>400</sup>

A more recent publication is *Models of Madness* by John Read and colleagues who present a review of the prevalence of sexual abuse and sexual trauma among female patients with schizophrenia and other forms of psychosis. <sup>401</sup> A prevalence of more than 50% of incestuous abuse and trauma is reported, and almost a 70% prevalence of one or another kind of sexual or physical abuse in childhood. The review covers 47 studies that have detected and presented sexual abuse among psychiatric patients of whom at least half were

<sup>&</sup>lt;sup>397</sup> Meaning that the subject is split and separated from the symptom or change, as if they were two different things.

<sup>398</sup> An example being Psykologtidningen nr 5 2008 which focused on childhood trauma as a cause of later psychic sufferings.

<sup>399</sup> Karon & VandenBos 1981

<sup>400</sup> Karon 2003, p. 7

<sup>401</sup> Read & Goodman et al. 2004

diagnosed as psychotic. 402 A similar review was done by Read et al in respect of male patients, showing similar figures: a prevalence of 28% of child sexual abuse was reported, and 51% child physical abuse. The sample was similar: male psychiatric inpatients and outpatients of whom at least 50% were diagnosed as psychotic. 403

John Read and colleagues have also done a reverse study, where they have shown how remarkably many patients with a documented history of sexual abuse later show symptoms of schizophrenia. In their study 75% of patients with a documented history of child physical abuse showed one or more symptoms of schizophrenia according to the DSM diagnostic manual, 76% of those who had suffered child sexual abuse showed one or more symptoms of schizophrenia and in the group subjected to incest 100% showed symptoms. Read and colleagues have also done reviews of studies connecting severe stress and abuse to different kinds of symptoms, showing that all four DSM characteristic symptoms of schizophrenia are significantly present in the 29 studies analysed. Conclusions drawn from a Dutch review article done by Janssen and colleagues in 2004 and referred to in *Models of Madness* are that those abused as children are nine times more likely to develop a "pathological level psychosis" and those suffering most severe level of abuse are 48 times more likely to develop psychosis. One of the property of the pro

Several more studies show a causal relationship between the experience of trauma and different psychotic disorders: publications by Lisbet Palmgren, Bertram Karon, John Read and co-workers, Alice Miller, Anna Luise Kirkengen, Suad al Saffar, Palle Villemoes, Wilfried ver Eecke, just to mention a few.<sup>407</sup>

What has also been published in research and theories is that the patient could, with the help of psychotherapy, structure, identify, accept and mourn the experiences, meaning they could heal, at least partially. This for example is proved and described by Barbro Sandin, Lisbet Palmgren, Jakko Seikkula, Alice Miller, Palle Villemoes etc. 408 If patients get the opportunity to talk about abuse, structure their memories, mourn with the help of professionals, they actually often have the ability to proceed without the most devastating symptoms. This must be an argument in favour of the contention that these phenomena, sometimes described as prodromes of schizophrenia, are not merely biologically isolated incurable processes but also processes in interaction with others as well as psychologically affectable or even treatable. It is not probable that psychotherapy would have as good an

<sup>402</sup> Read & Goodman et al. 2004, p. 224 table 16.1

<sup>&</sup>lt;sup>403</sup> Ibid., p. 224 table 16.2

<sup>404</sup> Ibid., p. 230

<sup>405</sup> Ibid., pp. 228-236

<sup>406</sup> Read, Mosher & Bentall 2004, p. 248

<sup>407</sup> Al-Saffar 2003; Karon & VandenBos 1981; Karon 2003; Kirkengen 2005; Miller 1981; Miller 1988; Palmgren & Sandin 2000; Palmgren 1997; Palmgren 1998; De Waelhens & Ver Eecke 2001; Ver Eecke 2004; Villemoes 1989

<sup>408</sup> Karon & VandenBos 1981; Miller 1981; Miller 1988; Sandin 1998; Seikkula 1998; Villemoes 1989

effect on fantasies or hallucinations created only by bio-pathological processes without a relation to an actual experience. Even though one can argue that psychotherapy could have some effect even on strictly pathological bio-physiological processes, it is probable that the effect would be greater on a realistic and experienced trauma and later sufferings. To be psychotic and in these cases also schizophrenic is a part of an answer to something for these patients, which is also an argument for the hypothesis that there is a dose and response relationship between abuse and later sufferings: the more severe the abuse, the more severe the effects. These patients' sufferings are so severe that the state they are considered to be in, agrees with the diagnostic manuals, descriptions of schizophrenia.

Since this hypothesis improves the chances of recovery, it includes hope. With an exclusively genetic or bio-physiological hypothesis concerning the cause of schizophrenia, the hope of recovery is quite small, often even absent. I would suggest that this hopefulness is essential for these patients. The opposite leads to the devastating fact that you have both experienced abuse and neglect and you are considered schizophrenic, and will be treated as schizophrenic. This kind of re-pathologizing does not pay due attention to the fact that it can burden the patients even more. To neglect and belittle experiences like sexual abuse will create greater feelings of shame and guilt and will prevent a proper encounter with the subject. Several researchers have pointed to this fact that is called "revictimization". To neglect and belittle earlier experiences will cause the patient to become a victim again and add to the negative experiences. Anna Luise Kirkengen has discussed this phenomenon in medicine and psychiatry today. 409

This will also be a possible interpretation of what could happen if a patient were diagnosed as having schizophrenia according to DSM or ICD. This in addition to the inability to any existential choice since there have not been any options of representations and many senses of the self have been severely harmed by the abuse and neglect will have consequences with regard to the patients' possibility of receiving adequate help and avoiding revictimization.

John Read says in the introduction to Models of Madness:

How hard it is to make psychiatrists realize the obvious fact that people are driven crazy by bad things happening to them. 410

Studies aiming at exploring a relationship between trauma and later effects have often been criticized partly because the definition of "negative experience" has been diffuse and wide, but that does not diminish the fact that negative childhood experiences, such as vio-

<sup>409</sup> Kirkengen 2005, p.137

<sup>410</sup> Read, Mosher & Bentall 2004, preface

lations and sexual abuse, do have long and lasting effects on the victims. One could then argue that maybe the most important initial thing is to accept that these experiences in fact do increase suffering, illness and disease on the whole. Furthermore since these negative experiences are a part of many patients' history it is important to take them into consideration regardless.

#### MORE TRAUMA-CAUSED EFFECT

To continue the discussion about the patients presented in this thesis I would like to high-light some other effects of child abuse. Studies that have shown a relationship between sexual abuse and more symptomatologically physical syndromes, and I will present some of them in the following.

A recent publication analysing the relationship between childhood trauma and later effects is the above mentioned Anna Luise Kirkengen's Hvordan krenkede barn blir syke voksne.411 Kirkengen is a doctor who found that sexual abuse was very often present in both women's and men's history even though the symptoms were very different. She presents a long list of different complicated and severe diseases and sufferings which in her study are shown to have a direct relation to sexual abuse. She also highlights the fact that sexual abuse both among children and grown-ups is much more common than is reported to doctors, psychologists etc. The number of unrecorded cases is believed to be great. Kirkengen maintains not merely that violations are transformed into diseases of different kinds, but also that the transformation is subject to sociocultural influences and that the disease and illness is often inadequately treated both within medical and psychiatric health care. 412 For Kirkengen it is certain that violations do develop into suffering and disease, partly because the body has not learnt to relax and be safe but is instead always afraid of further violations. This constant tension strains the body and makes it susceptible to further stress and disease. Another important factor is the difference between on the one hand understanding a disease and symptoms as demarcated parts, on the other hand perceiving the human being as an entity including a consistent history. Kirkengen stresses that no disease is without a history but she maintains that the medicine of today is not able to make the human being visible as the bearer of a history. 413 Kirkengen also highlights how actually well-known but little taken into consideration is the fact that mothers of abused children have most likely themselves been abused as women and very often

<sup>411</sup> Kirkengen 2005

<sup>412</sup> Ibid., p. 14

<sup>413</sup> Ibid., p. 20

also as small children. 414 Kirkengen points out the known fact that abused women often do live in unstable and destructive relationships as adults, this because they have no other experience. These women do not know any other ways of living – and, even more important, they have not learned to respect themselves. This means that they will not be able to teach their children to respect themselves either, which is in accordance with the theories of Alice Miller etc. 415 Kirkengen refers to many other studies showing the same thing, for example Vincent Felitti and co-workers on early death among patients with "negative childhood experiences". The conclusion of the mentioned study was that the effect of negative experiences was strong and cumulative. 416 Felitti et al and Kirkengen stress how common silence is about negative childhood experiences. Negative experiences have longlasting consequences and continue to affect people decades after. 417

Among women with negative childhood experiences the risk of an early death is increased by five times, states Kirkengen. 418 Kirkengen emphasises that fragmentary representations of these abuse experiences are often interpreted as something pathological and referred to psychiatry, without cause and without understanding of the history.<sup>419</sup> That is why these patients are often considered as psychiatric patients. In The Seeman Report, as well as in Foege, Krugman and Cohn, also referred to in Kirkengen's book, provides evidence of childhood abuse substantially increasing the risk of later disease and an early death. 420 These texts together with Mosher and Reads and others have demonstrated an undeniable correlation between early violation and later disease and early death. The ethical dimensions of ignoring these facts are also discussed in Kirkengen's book. 421 The ethical aspect is a complex question including medical science, valuations, understanding the lived body and so forth. The biomedical knowledge dominating the medical science of today is based on objective theories and methodology. According to Kirkengen the valuation of the human being is based on observations of groups of people alienated and abstracted from their individual characteristics. The body as the bearer of different diseases is then seen as something mechanical and purely material.<sup>422</sup> But no human being is such a body.

Not wishing to enter into a very complicated medical explanation of the exact relation between negative childhood experiences and later illness and disease presented thoroughly in Kirkengen's book, I just want to draw attention to one main fact, namely the constant

<sup>414</sup> Kirkengen 2005p. 30

<sup>415</sup> Kirkengen 2005, p. 31; Miller 1981; Miller 1988

<sup>416</sup> Kirkengen 2005, p. 31

<sup>417</sup> Kirkengen 2005, p. 31; Miller 1981; Miller 1988

<sup>418</sup> Kirkengen 2005. p. 32

<sup>419</sup> Ibid., pp. 33-36

<sup>420</sup> Ibid., p. 34

<sup>421</sup> Ibid., p. 35

<sup>422</sup> Ibid. p. 35

feeling of fear and the impossibility of feeling secure. Constant fearful stress in combination with other destructive factors such as violations and disrespectful and violating representations of early objects as well as violations of one's own body and self make adequate and healthy psychological development impossible. This situation strains the individual to such an extent that the whole system is always in a state of extreme tension. The violations of the self and the body as one's private spheres are also crucial with regard to the development from infant to adult. Kirkengen has made a thorough overview of recent studies, and her book is an important statement of the extended sexual abuse allowed worldwide. It is important to acknowledge regardless of what diagnosis the patient will get.

Another example is Hilde Nerum and colleagues study on Caesarean section in accordance with the wish of the mother-to-be. They interviewed a group of women that did not want to give birth vaginally, and the study design was much like that of the present study, with open interviews mainly governed by the patients and focusing on the entirety. It was found that 65% of these women had suffered sexual abuse. 423

Recent studies have also shown a kind of dose-response correlation between negative childhood experiences and later cardiovascular diseases. A study performed by Dong and colleagues in 2004 showed an even stronger relation between psychological risk factors such as sexual abuse and violation and traditional risk factors such as smoking and obesity. Exiktengen points out that these conclusions are supported by other studies. Goodwin and Stein in a study of 6000 adults found a strong correlation between negative childhood experiences and lung disease, gastric ulcer and joint diseases. Negative experiences, here including mistreatment, also led to higher risk of diabetes and autoimmune diseases etc. These results are supported by numerous other studies such as those of Stein, Barrett and Connor. The correlation between childhood experiences and later disease has also been studied with regard to cancer, bacteriological diseases, hormonological disturbances etc. The list can be made long.

There is probably some biological predisposition that predicts that these patients will respond with exactly these sufferings and expressions to the experienced trauma. I have no possibility of saying anything about the genetic predisposition in the present material. I have not had any medical aims and have therefore not done any medical examinations or tests. I am of the opinion, however, that there are always difficulties with a genetic hypothesis even if you do biological examination. There are in the present material examples of difficulties to ascertaining exact biological relations, difficulties with regard to methodical-

<sup>423</sup> Nerum et.al. 2006

<sup>424</sup> Kirkengen 2005, pp. 36-37

<sup>425</sup> Ibid., p. 37

ly investigating the full state of health during infancy since these patients are above the age of 18, and difficulties with regard to systematically investigating which different drugs these patients were treated with during childhood and adolescence as well as in fetus.

The discussion can of course then end up in the question of which factor is the *most* important causal factor. However, for this thesis this is not the central issue; instead the most important thing has been to show that there in fact *is* a likely relationship between the abuse and later sufferings, a relationship that it is vital to see as at least a part of the explanation and understanding of the sufferings.

#### LOST REACTIVITY

But if we assume that there is a causal relation between the traumata and the prodromelike phenomena reported by the informants, should these phenomena be characterised as prodromes of schizophrenia? Should not the traumas be viewed as partial causes of a reactive psychosis instead? I will attempt to describe some formal limitations in connection with using the DSM and ICD for such an option.

The first edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* appeared in 1952.<sup>426</sup> Many mental conditions were there defined as reactions to external phenomena, and:<sup>427</sup>

The use of the term "reactions" throughout the classification reflected the influence of Adolf Mayer's psychobiological view that mental disorders represented reactions of the personality to psychological, social, and biological factors. 428

For most of the disorders presented in the later versions DSM-III and DSM-IV no aetiological theories are presented. It is indicated in the introduction of DSM-III that a deliberate choice was made not to use terms to specify any causal hypothesis but instead use terms that "by a large did not imply a particular theoretical framework for understanding nonorganic mental disorders". The term "reactions" had already been replaced in DSM-II by more atheoretical diagnostic terms.

<sup>&</sup>lt;sup>426</sup> DSM-I 1952

<sup>&</sup>lt;sup>427</sup> DSM-III 1980, p. 1

<sup>428</sup> Ibid., p. 1

<sup>429</sup> Ibid., p. 2

However, possibilities of defining external stressors have been available in all versions, and external stressors have in the earlier versions been described as a possible partial cause of many different mental disorders, including psychosis.<sup>430</sup> In DSM-I the diagnosis Psychotic Reaction was placed in the group of other psychoses 20.x-24.x.<sup>431</sup> In DSM-II Reactive Psychosis and Psychotic Depressive Reaction were still categorized in the diagnostic group of psychoses.<sup>432</sup> Even in the third version of DSM Reactive Psychosis had a category of its own in the diagnostic classification among other psychoses 295-298.<sup>433</sup> The diagnosis of Reactive Psychosis was already under special investigation in the second version of DSM and was so until it was excluded from the fourth version. <sup>434</sup>

In the later versions of the manual the relation between external factors and a mental reaction is removed; no psychosis is directly presented as an effect or reaction to experiences any longer. <sup>435</sup> But it is possible to identify and specify child abuse *together with* psychosis in both DSM-III and DSM-IV, but on different axes. It is emphasized that the multi-axis classification, introduced in DSM-III, should ensure that attention is given to certain types of disorders, aspects of the environment, and areas of functioning that might be overlooked if the focus were on assessing a single problem. <sup>436</sup>

In these classifications, then, it is not explicit that a stressor can be seen as the cause of a specific psychotic suffering and there is no defined and explicit correlation between a specific happening and an effect. It is instead up to the diagnosing doctor to *judge* the situation.<sup>437</sup> These factors, defined on the other axes, are instead defined as problems that *may affect* the diagnosis, treatment and prognosis of the mental disorders specified in Axes I and II.

Let us return now to the present situation and consider some other potentially relevant diagnoses that exist today, for instance Brief Psychotic Disorder in DSM-IV 298.8<sup>438</sup> and

<sup>&</sup>lt;sup>430</sup> Still I am only discussing psychosis not caused by a defined physical condition. Defining psychoses as caused by physical conditions has always been, and still is, possible in the DSM system.

<sup>&</sup>lt;sup>431</sup> DSM-I 1952, pp. 83-84

<sup>432</sup> DSM-II 1968, pp. 7-9

<sup>433</sup> DSM-III 1980, p. 17

<sup>&</sup>lt;sup>434</sup> DSM-II 1968 xiv; DSM-II 1968 xv, The different versions of DSM have been closely related to the International Classification of Diseases ICD, and in the development of DSM versions have always been related to and partially based on earlier versions of ICD. A special group was summoned to solve the controversies around the diagnosis during the preparation of the second version. There was a need for operational definitions that could be used between Europe, the U.S. and the U.S.S.R.

<sup>&</sup>lt;sup>435</sup> The only exception may be the diagnosis of Post Traumatic Stress Disorder, as has been mentioned, but again PTSD is not a diagnosis in the category of psychoses, but the only diagnosis that is formally related to external stress.

<sup>436</sup> DSM-III 1980, p. 23

<sup>&</sup>lt;sup>437</sup> Ibid., p. 26

<sup>438</sup> DSM-IV 1994, p. 302

the corresponding diagnosis in ICD-10, Acute and transient psychotic disorder, F 23, where the stressor(s) can be specified and considered to be causes of the condition in question. <sup>439</sup> But according to DSM and earlier versions of ICD the stressful experience cannot have happened more than 1 month prior to these psychoses. This makes it impossible for such patients as have been abused for a long time like the ones presented in this study to get these diagnoses. PTSD – DSM-IV 309.81<sup>440</sup> and Acute Stress Disorder DSM-IV 308.3<sup>441</sup> are other possibilities, but they are not applicable to these patients. As soon as the patient becomes psychotic these diagnoses will be excluded. <sup>442</sup> In the latest version of ICD-10 the category Neurotic, stress-related and somatoform disorders is a possibility but only as long as the patients does not get psychotic symptoms. <sup>443</sup>

Another possible diagnosis is Depressive Disorder with Psychotic Symptoms but similar problems occur. A main difference between schizophrenia and other psychotic disorders is the duration of symptoms and/or sufferings. Symptoms must be persistent for more than 1 month for the illness to be called schizophrenia, and as soon as the symptoms have been persistent for that long the only option offered in DSM and ICD is schizophrenia. All the patients interviewed in this study had suffering and symptoms for over 1 month, with psychotic symptoms, and most of them had also been abused for years. It seems then that schizophrenia is the only remaining diagnosis for these patients.

A major problem with this diagnostic situation is that the concept of schizophrenia is struggling with the old connotation of severity, untreatability and often lifelong suffering. For this reason Ungvari, among others, in fact argues for the reintroduction of the category of reactive psychosis.

This underscores the importance of the reactive psychosis category in the differential diagnosis of acute psychoses. Without an empathic understanding of the patient's situation and the association between situation and clinical presentation, by cataloguing the symptoms alone the diagnosis could easily have been schizophrenia, schizoaffective psychosis or bipolar affective disorder. 444

The diagnosis of reactive psychoses requires the determination of the link between trauma, personality and psychosis, an exercise calling for experience, skill and considerable empathy on the part of the examiner. 445

<sup>439</sup> http://www.who.int/classifications/apps/icd/icd10online/

<sup>440</sup> DSM-IV 1994, pp. 424-429

<sup>441</sup> Ibid., pp. 429-432

<sup>&</sup>lt;sup>442</sup> Post Traumatic Stress Disorder with delayed onset is another possibility but excluded as soon as psychotic symptoms occur. (DSM-IV 1994 p. 429)

<sup>443</sup> www.who.int/classifications/icd 2008-10-06

<sup>444</sup> Ungvari & Leung & Tang., 2000, p. 622

<sup>445</sup> Ungvari, Leung & Tang, 2000, p. 623

Obvious in the cases examined in this study is the importance of a careful anamnesis and a talented and emphatic examiner with deep knowledge of personality organisation, psychiatry and the link between trauma, personality and psychoses. The force in Ungvari's analysis is that the absence of reactive psychosis as a valid diagnosis might reduce clinical psychiatry. It removes an important opportunity for understanding mental disorders in relation to earlier experiences as well as to psychological development and the social and cultural context. This will lessen our awareness of the link between psychosis and our common society. We seem also to lose sight of the connection between our life-course and our suffering. If "prodromal" phenomena are only considered as early signs or as precursors of something coming instead of effects of something, we might loose a means of understanding the suffering, as if life and suffering were separated phenomena. Another aspect of this is that the prognosis of the former category of reactive psychosis was optimistic and the patient was supposed to gain full capacity after a short time.

If a patient is reacting to, for example, sexual abuse, there is little possibility of taking this into consideration in the diagnosis.<sup>447</sup> Historically more severe diagnoses such as schizophrenia have never specifically included trauma. Conversely if there is no possibility of focusing on reactivity then the patient will end up with a diagnosis based on symptoms. The results of this study could easily be regarded as indicating that these patients were developing schizophrenia and treated as having schizophrenia, at the expense of loosing the phenomenological understanding of the suffering – the experienced illness – as well as a potential positive prognosis.

To summarize: it is an essential issue that trauma-related conditions sometimes appear the same as, or similar to, prodromal, prepsychotic and psychotic symptoms of schizophrenia as defined by DSM-IV and ICD-10 and current research on prodromes to schizophrenia. It is combined with great difficulty in distinguishing these conditions from each other by assessing only single symptoms or "prodromes". I even doubt it is always possible to separate them from each other – and sometimes even, the symptoms could be both an effect of something and a precursor of something coming.

And formally, as shown above, the possibility of characterizing these phenomena as caused by trauma has disappeared from the terminology in DSM-IV and ICD 10. Since the category of reactive psychosis does not (formally) exist the traumata cannot be partial causes of reactive psychosis. The prodromal phenomena could then be understood as precursors of some other psychosis. Schizophrenia seems to be the only formal possibility according to DSM-IV. But what does the terminology say about causes of schizophrenia?

<sup>446</sup> Ungvari & Mullen 2000; Ungvari, Leung & Tang 2000

<sup>447</sup> Meaning Axis 1 and ICD-10. Again there is a possibility of defining other axes in DSM IV such as Psychosocial and Environmental Problems (Axis IV) but strictly in the diagnosis this possibility does not exist.

#### Part D

As has been shown above: nothing. Thus, if we accept my causal hypothesis schizophrenia could then (indirectly) be partially caused by traumata.

This is a formal limitation that can generate negative consequences, since schizophrenia, as we have noted above, has special connotations with regard to stigma, chronicity and treatment intervention.

# ANTIPSYCHOTIC PRIMARY PROPHYLAXIS – A CONSEQUENCE OF INTERPRETATION

I will now discuss a problematic key consequence of defining these phenomena as prodromes of schizophrenia, namely medical treatment.

One can argue for the importance of different early interventions in schizophrenia and other severe conditions, for example reducing the social complications that are connected with severe psychiatric conditions. There is also an increased risk of suicide, and a small but increased risk of aggression early in schizophrenia and other psychotic disorders, which it is argued can be reduced through treatment. Not forgetting the economic advantage of lessening the cost of treatment in schizophrenia both at the community level and the individual level. If the purpose is to protect the individual and lessen the cost the argument is understandable. Nevertheless, if the condition is identified as early as in a prodromal phase and treated as schizophrenia, the reasoning is not rational.

But the first question is whether psychopharmacological treatment in the prodromal phase of schizophrenia actually leads to a better prognosis. It has been debated whether drugs reduce the risk of, or even affect, a progression into schizophrenia if used even in a prepsychotic phase and logically, not in a prodromal phase. One can, though, argue that negative consequences of a severe psychiatric condition are reduced if intervention is successful, consequences of the psychosocial character such as loss of work or problematic relations with relatives, but psychosocial effects are rarely treated with drugs. Despite this many studies on treatment of the schizophrenic prodrome are on drugs and the outcomes of drug treatment.

If one believes in the hypothesis of psychopharmacological treatment in early phases of an assumed psychotic process and that they indeed decrease the risk of progression into schizophrenia, the pressing question that presents itself is that of transition rates. Taking into account the current results from research on the prodromal phase of schizophrenia, one has to regard treatment interventions in this phase as preventive. It is then of great importance to consider how many of those that could be preventively treated would develop schizophrenia without such treatment. (Again, in this chapter I am reasoning about strict psychopharmacological treatment.) It has been shown in reviews that the transition rates can vary from 9% to 70%. 448 This leads to the conclusion that in the group that

<sup>448</sup> Haroun, et al. 2006, p. 168

could be preventively treated the number of false positive patients, could be as many as 91%! Thus a very large percentage of patients may show prodromal or prodrome-like-phenomena, for reasons that have nothing to do with schizophrenia, yet be treated for schizophrenia or a coming schizophrenia, nonetheless. There is a risk, then, of treating 30 to 91% of the patients incorrectly as having early signs of schizophrenia!

The nonspecificity of the prodromes of course also reflects the nonspecificity of the schizophrenia syndrome. There are very many other, very diverse non-psychiatric conditions, besides those analysed in this thesis, that can cause phenomena the same as or similar to those associated with schizophrenia. Examples of such conditions are metabolic disorders, endocrine disorders, nutritional deficiency states, autoimmune disorders, motor disorders, Myelin disease, substance-induced disorders and infections.<sup>449</sup>

Despite this it is easy to find positive attitudes towards interventions in an early assumed psychotic process. In the Norwegian government document on the treatment of schizophrenia, *Statens helsetilsyns råd*, the non-specificity of current prodrome research is underlined but at the same time the importance of early medical intervention is emphasized. <sup>450</sup> In Sweden the possibility of treating psychosis prophylactically with olanzapine has been discussed. <sup>451</sup> Also Paul Møller recommends early medical interventions. <sup>452</sup>

In *Stahl's Essential Psychopharmacology*, the attitude towards treatment in the prodromal phase of schizophrenia is evidently positive. <sup>453</sup> It is confirmed that many studies have already shown positive effects of early pharmacological treatment in early first-episode psychosis and even the prodromal phase of schizophrenia: "early results with atypical antipsychotics are indeed promising" It is interesting that the handbook discusses the possibility of pharmacologically treating persons in a condition even *prior to* the prodromal phase, where the patient has no symptoms and where there is no possibility of verifying schizophrenia; they call it presymptomatic treatment of schizophrenia. <sup>455</sup>

It is also affirmed that "innovation in the area of schizophrenia is among the most actively researched areas in psychopharmacology. New concepts of prodromal and presymptomatic treatment to prevent disease progression as well as new mechanisms aimed primarily at the devastating negative and cognitive symptoms of schizophrenia have cap-

<sup>449</sup> For a complete summary of different nonpsychiatric conditions associated with Psychosis see White et al. 2006

<sup>450</sup> Statens helsetilsyn 2000, p. 13

<sup>450</sup> Ibid., p. 11

<sup>&</sup>lt;sup>451</sup> Janus info.se 2006-08-02, an article from 2003 based on Patrick McGorrys study; McGorry et al. 2002, pp. 921-928 and McGlashan et al. 2003

<sup>452</sup> Møller 2001, p. 11

<sup>453</sup> Stahl 2008

<sup>454</sup> Ibid., p. 439

<sup>455</sup> Ibid., p. 439

tured the imagination of new drug discovery efforts."<sup>456</sup> At the same time schizophrenia is described as most often incurable and "schizophrenic patients rarely achieve wellness, no matter what drug or drug combination is given".<sup>457</sup> It is also stated in Stahl to be a "dirty little secret" that most patients diagnosed as having schizophrenia, despite the recommendations, are treated with more than one antipsychotic drug simultaneously: "the use of two antipsychotics seems to be one of the most practiced and least investigated phenomena in clinical psychopharmacology.... it has not proven useful to combine two antipsychotics to get supra-additive antipsychotic effects, such as 'wellness' or 'awakenings'".<sup>458</sup>

This brings up the following question of the effects and side-effects of available antipsychotic drugs. All drugs available today have severe side-effects and some side-effects are actually similar to a progression of schizophrenia. A comparison between side-effects of most often used antipsychotic drugs and prodromes of psychosis shows how the two could easily be mistaken for each other.

One specific example is the side-effect emotional decline that is similar to the prodromal and the prepsychotic symptom where a patient, because of the inner chaos, becomes more and more introverted and is seen from the outside as more emotionally diminished. These have nothing in common since the latter is instead a sign of chaos and confusion and the former is an effect of the drugs. Similarly, the effects and side-effects of benzo-diazepine drugs, can give hallucinations and aggression which can be seen as a negative development of the psychosis. Even the editors of the DSM-IV, as well as several other researchers and practitioners, warn of this. Other examples that can be given are motor restlessness, cognitive blunting, social withdrawal, anxiety, nausea, dizziness, dry mouth, apathy, somnolence, increased appetite, fatigue, vomiting, urinary incontinence, increased salivation, depression, suicide, sleep disturbances.

This leads to the following: if phenomena are psychopharmacologically treated as early signs of schizophrenia, accepted side-effects of the drugs are similar to a developing schizophrenia! So if the patients would get side-effects there is an obvious risk that he or she will be considered as having developed more and/or stronger symptoms of schizophrenia and will get more psychopharmacological drugs. Catch 22 indeed!

<sup>456</sup> Stahl 2008, p. 439

<sup>457</sup> Ibid., p. 437

<sup>458</sup> Ibid., p. 437

<sup>&</sup>lt;sup>459</sup> This dilemma is discussed by Cullberg 2006 p. 279 among others.

<sup>460</sup> Cullberg 2006, p. 81-82; p. 267; Read et al. 2004, pp. 101-114, 115-130; DSM-IV 1994, p. 280

<sup>&</sup>lt;sup>461</sup> For further details see: Janssen-cilag at <a href="https://www.janssen-cilag.com">www.janssen-cilag.com</a>, producer of Invega and Haldol; or Bristol Meyer Squibb <a href="https://www.bms.com">www.bms.com</a> producer of Abilify.

Another important thing is that if treated with conventional antipsychotics, "about 5 percent of patients maintained on conventional antipsychotics will develop tardive dyskinesia every year (i.e., about 25 percent of patients by 5 years) – not a very encouraging prospect for a lifelong illness starting at the twenties." 462 Many times tardive dyskinesia is irreversible, and there is very little treatment option for patients that have developed this condition.

Since conventional antipsychotic drugs have proved to have such severe side-effects, tardive dyskinesia being one, so-called atypical antipsychotics started to be used over a decade ago, and for example the risk of chronic tardive dyskinesia was reduced. Now when the atypical drugs have been used for some time other serious side-effects have occurred; cardiovascular diseases, for example, that are caused by changes in metabolism due to treatment.<sup>463</sup> These side-effects do in fact result in: "death and loss of 20-30 years of normal lifespan".<sup>464</sup>

In view of the fact that the atypical antipsychotics have these serious side-effects, and more cost, some believe there will be a trend among psychopharmacologists to return to conventional antipsychotics, even though the risk of tardive dyskinesia still remains. 465 It is also worth emphasizing that very little systematic clinical research on antipsychotic drugs has been performed without pharmaceutical industry support. 466

Another important often stated hypothesis is that untreated psychosis has a degenerative and toxic effect on the brain. This is one hypothesis often added when arguing for early intervention. The first publication on a probable toxic effect was published by Richard Wyatt and was published in the *Schizophrenia Bulletin* in 1997. 467 In that article he speculates on the possibility of a neurotoxic hypothesis but emphasizes that there is no scientific evidence to support such a hypothesis, he instead discusses from his own clinical experiences. Wyatt has many times after that regretted his article published since he has been so misquoted. Several studies have tested the hypothesis without finding any proof of a neurotoxic effect on the brain during untreated psychosis. 468 Despite this, the hypothesis is often used when proposing early intervention in psychosis.

<sup>&</sup>lt;sup>462</sup> Stahl 2008, p. 333; "Thus, the number of patients that a psychopharmacologist need to treat in order to harm 1 patient with tardive dyskinesia may be only 4 young patients over 5 years of conventional antipsychotic treatment. Statisticians sometimes call this the "number needed to harm" ". (Stahl 2008, p. 333)

<sup>463</sup> Stahl 2008, p. 388; p. 385

<sup>464</sup> Ibid., p. 389

<sup>465</sup> Stahl 2008, p. 342

<sup>466</sup> Jeste & Glick 2000, p. 530

<sup>467</sup> Whyatt 1997

<sup>468</sup> Example of such studies are: Norman et al. 2001; Ho et al. 2005; Bola 2006

Further the question is how intimidated the patient, personnel, relatives and colleagues are by someone who is defined as being in an early state of schizophrenia or possibly being fully schizophrenic. The stigma must be devastating, especially considering that there is little effective treatment. A biologically oriented classification of the so-called prodromes could concentrate more on defined entities instead of on a more coherent and phenomenological understanding of patient's experiences. As an alternative interpretation reactive psychosis, in contrast with schizophrenic psychosis, has a positive prognosis.

Essential for this thesis is therefore of course how these patients' sufferings are treated within psychiatry. The obvious example is how a patient should be treated if he or she fulfils the criteria for schizophrenia according to DSM-IV and ICD-10, but when the symptoms are assumed to be partially caused by traumatic experiences? Such a patient has a different recovery potential according to trauma theory in psychology as well as schizophrenia theory, as presented in DSM. If a patient fulfils the criteria for schizophrenia regardless of why, he or she could be treated as schizophrenic according to DSM, with all that that means in the way of side-effects of drug treatment, negative stigma, negative prognosis potential etc. But if the suffering is instead treated as the effect of trauma and the patient happens to be cured, the diagnosis of schizophrenia could be questioned since a negative prognosis is mandatory for the definition of schizophrenia according to the manuals to some extent and the received view to the full extent. The case of Barbro Sandin's patient Elgard Jonsson may serve as an example. 469 Barbro Sandin is a famous but controversial psychotherapist working with patients who have severe psychotic symptoms. Elgard was admitted to a locked psychiatric division, diagnosed as having schizophrenia according to the diagnostic manuals and treated as a schizophrenic for many years. Many years later he met Barbro Sandin and during the therapy administered by Sandin he became symptom-free, ceased his medication and gained insight. He now lives a normal life, successfully completed an education to become a psychologist and is now working as one. Elgard proved to have psychological trauma, which was treated and cured by Sandin. Many experts have criticized Sandin for stating that she cured a patient with schizophrenia. This criticism is based on the assumption that because Elgard was cured, he could not have had schizophrenia. Prior to his being cured, however, over a period of many years he was treated as having schizophrenia because he presented all the listed symptoms. The same story is observed in the case of patients treated by Bertram Karon, Alice Miller, John Read, Bertram Karon, Palle Villemoes among others. 470 This example highlights the discussed risk of using the DSM and ICD diagnosis of schizophrenia and

<sup>&</sup>lt;sup>469</sup> Sandin 1998; as well as Elgard Jonsson 1996. his own telling is published in his book *Tokfursten*.

<sup>&</sup>lt;sup>470</sup> Karon & VandenBos 1981; Miller 1981; Miller 1988; Villemoes 1989; Sandin 1998, Karon & VandenBos 1981; Seikkula 1998

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the risk involved in neglecting information about essential experiences and factors in the patient's life that could contain a possibility for recovery. Another main argument is that there is an important difference between schizophrenia as defined in DSM and ICD and conditions as effects of trauma. Since DSM does not discuss causes and effects, and therefore not possible cause of schizophrenia, the focus will not be on likely or obvious stressors, or on experiences related to the suffering. These are questions currently much debated and in need of further discussion and analyses.

### 8 EPILOGUE – A NEW SUMMARY

When this study started, research on prodromes of schizophrenia was attracting much attention. Prodromes were seen as a kind of herald of a coming psychosis, often a schizophrenic one. Various kinds of features were discussed and presented as key factors in identifying and preventing a schizophrenic process. Was it perhaps possible to identify a coming schizophrenia prior to the actual onset? Many researchers and practitioners were optimistic and expectant concerning these new findings. The discussion was also on the possibility of preventive medical treatment in the prodromal phase to minimize the negative effects of a full-blooming psychosis. At the same time very few articles discussed the different dilemmas with regard to preventive treatment and identification. As I understood the research after going through published material on prodromes of psychosis up until 2002, the tendency was to believe in the positive effects of preventive medical treatment in the prodromal phase. But one could also easily be puzzled by the diversity of "prodromal research".

I was early confused about some quite extreme variants of "prodrome phenomena", such as the theory that "the nose knows" just to give one example. The Nose Theory was presented in October 2003 in *ScienceDaily*<sup>471</sup> with the headline: "Could you suffer from psychosis? The Nose Knows." The article presents research from Australia where researchers at the University of Melbourne examined a group of people at ultra high risk of developing schizophrenia and showed that the patients had difficulty in identifying smells. It was suggested that one could do a nose, or smell test to detect schizophrenia in the prodromal phase. The study was published in the *American Journal of Psychiatry*. It has also been suggested that a dramatic change of hairstyle could be a prodromal sign of schizophrenia. A study done by Joost Campo and colleagues has suggested that a drastic change of hairstyle is related to schizophrenia, and even more specifically to disorganized type of schizophrenia. <sup>472</sup> Could it be just a matter of time before dramatic or drastic hairstyle change could be a sign of a coming schizophrenic psychosis? Campo and colleagues,

<sup>471</sup> http://www.sciencedaily.com/releases/2003/10/031029064717.htm, 2008-05-14

<sup>472</sup> http://www.tijdschriftvoorpsychiatrie.nl/en/register/articles.php?pgr=8&year=1996, 2008-05-14

article was published in *Acta Neuropsychiatrica* in April 2007.<sup>473</sup> Early detection seemed to be a fascinating though somewhat scary field of interest.

The situation was also this. Schizophrenia is one of psychiatry's most severe and stigmatizing diagnoses. Of course it would be of great interest for everyone – patients, psychiatrists, relatives and society – to be able to reduce this condition which today is so destructive. Schizophrenia is often presented as an inherited brain disease with very little interaction with a person's experiences in life. This interpretation has had the effect that many patients have been, and still are, treated with electroconvulsive therapy and antipsychotic medicines, often with severe side-effects, and treated against their will at in-patient clinics. The condition diagnosed as "schizophrenia" is a severe one and generates relentless suffering for patients and relatives, not to mention the socio-economic effects.

In this study I interviewed a group of patients that – according to my analysis theoretically – were in a prodromal phase of psychosis. I wanted to analyze what kind of patients you would find if you used some new knowledge about the prodromal phase of schizophrenia.

The result was that I found *many* of the so-called prodromal phenomena in all patients. It was soon obvious that I had chosen the correct group of patients: many of the patients were later diagnosed with schizophrenia or other mental conditions including psychosis, meaning I had found patients that could have been diagnosed as being in an active prodromal phase of schizophrenia.

If diagnosed – without regard to their earlier experiences – these patients could theoretically fulfil all the criteria of schizophrenia according to ICD or DSM. These patients could then be labelled as schizophrenic according to DSM-IV or ICD-10, treated as schizophrenic, and maybe remain schizophrenic. The diagnoses could be self-fulfilling and the future as predicted.

So was I satisfied with this? The results could be an argument for the possibility of actually finding the discussed phenomena prior to the onset of schizophrenia. But no, I was not satisfied by this because I found much more information in the interviews. It was soon obvious that almost every patient had been severely traumatized by long-term abuse, often sexual. The patients told me about extreme abuse and phenomenological information was given about the sufferings which had led to the need for psychiatric care; and almost all the patients described a relationship between the abuse and current psychiatric problems. After this study I am convinced that most of these patients' sufferings were caused, or at least partially caused, by long-term sexual and physical abuse.

<sup>473</sup>http://pt.wkhealth.com/pt/re/acnp/abstract.00012993-200704000-00005.htm;jsessionid=LrCLLsXRb19tjkPJTghZsbRXD9vxc7p674nxFx7038WKypGCktZTl298990308!181195629!8091!-1, 2008-05-14

The question is what these phenomena that I found really were then. I wonder: did I not actually find the *real* group later diagnosed as having schizophrenia or other psychoses? Maybe this was the reality in this sample? May some patients have been abused, leaving experiences which later caused severe suffering, suffering which later was manifested in symptoms appearing to be in accordance with the diagnostic criteria of schizophrenia in ICD and in an early stage also with so-called prodromes according to published studies? The questions is, what will be the consequences of calling these phenomena prodromes of schizophrenia, and are these patients *real* schizophrenics or not? But of course I have also come upon the difficult question of the definition of "schizophrenia".

When I present these findings especially to psychiatric researchers and practitioners I am often criticized for having the wrong patients. It is not, I have been told, true that these patients have become schizophrenic because of their early abuse experiences but they have – just by coincidence – happened to also be abused, to some extent even maybe because they were in an early phase of schizophrenia. I have furthermore been told that my patients simply have been misdiagnosed, they should never have got the diagnosis schizophrenia. I have therefore been criticized for not having *real* schizophrenic patients (?) and consequently not *real* prodromes (?).

But I am sorry. This was exactly what I wanted to analyse. What happens if one uses knowledge about prodromes of schizophrenia as early as in an active prodromal phase? In accordance with my critics my study shows that it is extremely complicated to identify so-called prodromes of schizophrenia in this very early phase – just because you will apparently get – so to speak – the wrong patients. This could lead to their getting a severe diagnosis from the beginning, a diagnosis that it is very hard to get rid of. In this study almost all the patients were severely abused. By coincidence or not, I have interviewed the majority of patients that got the diagnosis schizophrenia according to ICD in the region during a period of two years. It is in any event rather remarkable that so many of these patients had been so extremely abused. Abuse is not traditionally an inclusion criterion for schizophrenia according to ICD. For me it is important to highlight that the phenomena could be both partially caused by trauma and predicting a coming schizophrenia, maybe both on equal grounds. I have argued that it is a problem to exclude the trauma especially as early as in the so-called prodromal phase and that it will lead to consequences for the patients if defined as schizophrenia.

But let me first try another thing. Assume that my patients are – so to speak – misdiagnosed, assume that they should never have got the diagnosis of schizophrenia. The natural thing to believe then is that they should be diagnosed as victims of extreme circumstances with marked stressor(s), which eventually led to the mentioned sufferings. This could then include trauma as the, at least partially, causal factor. But this does not actually help, since there is little possibility of diagnosing their sufferings as partially caused by something like

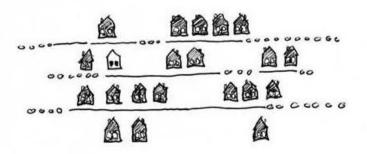
long-term childhood sexual abuse in the psychiatric manuals most often used today. The diagnosis Reactive psychosis was a possibility in earlier versions of DSM but in later versions removed.

The patients in this study were themselves convinced that the trauma was the main cause of their sufferings, and I have tried to argue for the *importance* of acknowledging and investigating such causal factors.

My point is that there are obvious limitations in possible diagnostic options in such cases as described in this thesis, if the diagnostic manuals DSM-IV and ICD-10 are used. In combination with the received view and stigma effects attached to the diagnosis of schizophrenia, this is a key topic for this thesis and obviously for future patients.

There are probably many possibilities of getting the diagnosis of schizophrenia, but the examples in this study show that long-term abuse, often sexual actually can trigger psychiatric conditions corresponding to the definition of "schizophrenia" according to DSM and ICD. Consequently, the conclusion I must draw from this study is that trauma and/or neglect is a likely partial cause of schizophrenia. And therefore, we must acquire a much broader understanding of the phenomenon of schizophrenia, as well as of the means to treat this illness.

# PART E -



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