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**SUICIDES, PSYCHOTIC  
DISORDERS AND  
CRIMINALITY AMONG  
FORMER CHILD AND  
ADOLESCENT PSYCHIATRIC  
PATIENTS FOLLOWED INTO  
ADULTHOOD**

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Institutet**

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*To get through the hardest journey we need take only one step at a time, but we must keep on stepping. (Chinese proverb)*



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## ABSTRACT

The overall aim was to provide information about child and adolescent psychiatric (CAP) patients and their outcome as adults: Were their difficulties in childhood due to mental illness, disablement and/or behaviour disorders? What happened to them as adults? Who were the patients in need of psychiatric care (GenP) in adulthood that had not had previous contact with CAP? Did this group differ from the former CAP group?

**Methods:** Paper I-III: 1,400 CAP patients admitted 1975-1990 to inpatient or outpatient CAP care in Jämtland County, Sweden were followed until 2003. Paper IV: A sample of 167 GenP patients not treated in CAP was compared to GenP patients with a history of CAP care. Hospital records at CAP were reassessed according to a study specific protocol. Outcome was measured in relation to register data on mortality, suicides, psychiatric/somatic care, and criminal convictions. CAP records were examined for those treated for psychosis either at CAP and or in GenP.

**Results:** Every third CAP patient has later received GenP care. They constituted a small part of the GenP patients in the same age-groups. The CAP patients showed an elevated rate of early death. Two of the 19 who later committed suicide had been initially admitted because of attempted suicide. Every third CAP patient had a criminal record. Over the past 50 years, the percentage of Swedish boys admitted to CAP care and later registered as criminals seems to have doubled while the corresponding percentage for girls has increased almost seven times. Behavioural disorders as a reason for CAP care were the most substantial risk factor for later criminality. Sixty-two former CAP patients (4.4%) received a psychosis diagnosis during the observation time 48 of them within the Schizophrenia categories and 14 with Psychotic Mood Disorder. Mean age at first onset was 21.4 years. Changes in behaviour, including social isolation, refusal to go to school, loneliness and odd behaviour in general were the initial signs and symptoms most frequently observed prior or upon admission to CAP-care. The GenP patients with and without a previous history in CAP care had similar problems as adults. Both groups had a larger need of somatic hospital inpatient-care before the age of 18 years when compared to the general population. More than a third of the treatment occasions occurred in paediatric care.

**Conclusions:** Psychosocial risk factors and social maladjustment in childhood seem to be the most important predictors of early death, including suicide. The increased risk of later criminality is hypothetically the result of rising alcohol consumption in Sweden, the comorbid use of illegal drugs, and changes in the organization of child social welfare work, the school system, and CAP methods that has occurred since 1970. Patients with onset of schizophrenia before 13-17 years of age showed typical symptoms upon admission to CAP care; while late-onset psychosis among former CAP could not be predicted from information gathered during CAP care. There is a group of patients treated in paediatrics and in CAP during childhood and adolescence before becoming later patients in GenP. These patients can most likely be identified during childhood if a closer collaboration is developed between paediatrics and CAP services. Hypothetically, the need of GenP care as adults in the larger group of GenP patients without a previous CAP history may develop from accumulated stressful life-events.

**Keywords:** Psychiatry, child, adolescent, adult, mortality, suicide, crime, mental disorders, psychotic disorders, paediatrics, longitudinal studies

## LIST OF PUBLICATIONS

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- IV. Engqvist, U. and Rydelius, P-A. Young adult and middle-aged psychiatric patients - a comparison of those with and without a history as recipients of child and adolescent psychiatric care. Manuscript

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## LIST OF ABBREVIATIONS

ADHD	Attention-Deficit/Hyperactivity Disorder
APA	American Psychiatric Association
BRÅ	Brottsförebyggande rådet (The Swedish National Council for Crime Prevention)
CAARMS	The Comprehensive Assessment of At Risk Mental State
CAP	Child and Adolescent Psychiatry
CI	Confidence Intervals
DSM	Diagnostic and Statistical Manual of Mental Disorders
GAD	Generalized Anxiety Disorder
GenP	General (adult) Psychiatry
IACAPAP	The International Association for Child and Adolescent Psychiatry and Allied Professions
ICD	International Classification of Diseases
LVM	The Care of Alcoholics, Drug Abusers and Abusers of Volatile Solvents Act.
NCCP	The Swedish National Council for Crime Prevention (BRÅ)
OR	Odds Ratio
PBU	Psykiatrisk Barn- och Ungdomsvård (Child Guidance Clinics)
R&D	Research and Development
RR	Risk Ratio
SCB	Statistiska Centralbyrån (Statistics Sweden)
SD	Standard Deviation
SiS	Statens Institutionsstyrelse (The National Board of Institutional Care)
SMR	Standardized Mortality Ratio
SPSS	Statistical Package for the Social Sciences
UHR	Ultra High Risk
WHO	World Health Organisation

# 1 PROLOGUE

“The Long and Winding Road” is not only a ballad written by Paul McCartney, it serves also as a description of this work.

In 1981 when I had recently graduated from the School of Social Studies, I worked as a hospital almoner at a ward at the Frösö hospital in Östersund, one of the old Swedish Mental Hospitals and in 1981 the psychiatric hospital of the Jämtland County. At “my” ward, young patients with psychoses were treated with the goal to give them opportunities to a life outside the hospital. I met with two young patients, a man and a woman in their early twenties, whose psychiatric histories incited my interest in the processes involved in the transfer of young patients from CAP to GenP when they legally become adults at 18 years.

It was evident from their hospital records and the information from the staff that the transfer between the two departments had not been free of problems. The view on their symptoms and the treatment differed when comparing the two disciplines. As I discussed more with the young patients I became more and more interested in the life histories of young psychiatric patients, their experiences of their stay at the CAP wards and what their future would be. One conversation in particular has stayed in my mind. The young man, sitting in an armchair, was breathing deeply and loud. “What’s up?” I asked and he answered — “I am training, training to become like the “oldies” in the ward upstairs.” My immediate reflection was about the depressing view on the future he had.

A year later, I started my employment at the CAP Department in the same hospital organization. This position I was meant to have for twenty years. I spent the first five years at the inpatient ward that offered a combination of emergency care and short term treatment, as well as longer treatment periods for children and youths. The inpatients were boys and girls with more serious symptoms and behaviour problems, often with a problematic psychosocial background and home situation. During those five years several occasions influenced me to often reflect on the future of these patients.

From 1988, I changed from working with inpatients to do outpatient care. Tom Åberg, the head of the Department encouraged me also to work with evaluation and statistics, and in September 1989, I became responsible for the R&D activity at CAP. I started to collect statistical information about the patients visiting the clinic regarding how they were treated and what the outcomes were in order to begin to answer the questions often asked by hospital executive officials and external visitors about the outcome of treatment and the prognosis of the patients. This was appreciated from the hospital authorities. In 1993, I received a grant from the Jämtland County Council to write a research plan for my project with the aim of describing CAP-patients, their need of later GenP care and their situation as adults.

In April 1997, I was accepted as a postgraduate student at the Department for Woman and Child Health, the unit for Child and Adolescent Psychiatry at the Karolinska Institutet in Stockholm with Professor Per-Anders Rydelius as my supervisor. My work

setting up a study protocol, searching for missing personal code numbers at the provincial record office and the local tax authorities and scrutinizing hospital records. The first article produced on this topic was published in *Läkartidningen* [1]. In 2002, I defended my licentiate thesis where patient data from time periods of 5-20 years were presented together with data from questionnaires and interviews comparing staff groups within CAP and GenP respectively about their knowledge of children and youth and their perceptions on counterpart's activities [2].

The findings from my licentiate thesis have now been elaborated to a doctoral thesis with the aim of describing different aspects of the outcome in adulthood for 1,400 former CAP patients, and as well a comparison of GenP patients with and without a history as recipients of CAP care.

During my research I have had the opportunity to again meet the two patients I first treated in 1981. In the early 1990s the Community Mental Health Care reform was accepted in Parliament and successively implemented in Sweden. Both patients have benefitted in many ways from the reform. Today they live outside the hospital in small groups in sheltered housing. The male patient works in sheltered employment, but nevertheless, he is employed and has a much better quality of life compared to our first meetings.

This doctoral thesis marks the end of a long and winding road but also reveals new pathways for future research on the quality of life of patients with severe psychiatric conditions - research aims that I have found both necessary and important.

## 2 INTRODUCTION

### 2.1 PSYCHIATRY, A LARGE SCALE CARING SECTOR

Psychiatry, the branch of medicine devoted to the diagnosis, classification, treatment and prevention of mental disorders as defined in the Oxford dictionary of psychology, is one of the most large-scale caring sectors in our time. It is probably the most changeable, and widely prejudice loaded sector in the health care system in Sweden. Among the most rapidly growing, controversy-ridden, and attention-attracting area of history over the past generation has been the history of psychiatry [3-6].

*“During the last three decades, debates have raged concerning the rise and fall of the asylum; the history of compulsory institutional confinement and de-institutionalization; the origins, scientific validity, and therapeutic efficacy of Freudian Theory; the merits of biological as opposed to psycho dynamic models of the mind; the history of the insanity plea in the courts; the past uses of extreme physicalistic treatments for mental disability, such as frontal lobotomies and electroconvulsive therapy; and most recently, the role played by psychiatry in the alleged processes of social and sexual control applied to women, workers, ethnic minorities, and gay people. The last thirty years have brought an outpouring of original scholarship-often passionate, partisan and polemical-in all of these areas with no sign at present of slackening” [5] page 3.*

Suffering from grave mental illness is in most cases something that shakes up and obviously changes life for an individual. Often it implies consequences to those around him and affects largely those closest to him. Mental illnesses and dysfunction influence our feelings and thoughts and makes us more vulnerable than otherwise. Maybe that’s why many of us fear the idea that mental illness may strike anyone [7].

Psychiatry is not at all a uniform concept. In Sweden, there are three psychiatric settings, GenP, forensic psychiatry and CAP [8, 9] working with adult patients, children and young people up to 18 years and mentally disordered offenders, respectively [8].

Without being a speciality there are also units for geriatric psychiatry in some hospitals. Particularly, in the research work delimitation of psychiatry is made with consideration to method and theoretical basis in for example dynamic psychiatry, social psychiatry and biological psychiatry [10].

People are individuals in a social context. As individuals we have biology and psychology. Psychiatry must work within these three perspectives: the biology, psychology and social factors entail that psychiatry to a lesser extent than other medical fields of science is based on scientific oriented research [8]. This is also evident in both the scientific origins and in different collaboration contexts for both GenP and maybe in particular for CAP.

The psychiatry historical research has undergone a powerful expansion since the 1960s and during this time the psychiatric care arrangements and psychiatry as an interdisciplinary activity above all has been the object for mass media attention without counterpart during earlier periods [4].

During the last 40-50 years much has happened both in the organization and practice of psychiatric care for adults as well as for children and adolescents.

## **2.2 GENP AND CAP**

There are many similarities between GenP and CAP. Despite this there is a lack of significant and reliable information regarding, for instance the relationship between psychiatric deviations and behavioural disturbances in childhood and psychiatric disorders and social adjustment problems and or criminality later in adulthood. Information about the relationship between behavioural disturbances in childhood and criminality in later life has however developed further compared to information about psychological deviations during childhood and later psychiatric illness. There is also a virtual lack of information regarding possible early symptoms of mental disorders, and how they change during the process of maturing from childhood to adulthood.

Overarching knowledge concerning co-operation between CAP and GenP is missing, especially about how this should be planned to be optimal for the patients and their relatives.

A description of knowledge and valuation about each other using a comparison of staff groups within CAP and GenP was presented in my licentiate's dissertation at Karolinska Institutet. An inquiry study comprising 100 personnel indicated that there were deficiencies within GenP care concerning the knowledge of children and adolescents and that there were differences between the settings in approach and methods of practice. The basic training within the nursing occupations ought to be improved regarding CAP and in further training knowledge of each other's area should be included. The organization within the hospital was considered as an obstacle for co-operation. The changeover for patients from CAP to GenP was seen as a problem of both the personnel categories. Therefore, an interest emerged for co-operation concerning youths and an objective to approach each other from the needs of this group [2].

It is possible to describe the difference between the two psychiatric settings.

**CAP** works with psychopathological states of the growing and maturing individual or personality where the psycho pathological symptoms change in pace with maturity. Historical descriptions show how origins of the psychiatric activities and the approach differ and how the two settings have developed in somewhat different directions during the whole 20<sup>th</sup> century.

The population of Swedish CAP patients is heterogeneous; and include children who demonstrate problems at school with adjustment and behavioural symptoms and/or psychiatric problems, as well as children with psychosocial, family related difficulties [2, 11, 12]. Heterogeneity within groups of psychiatric patients poses problems for theory, research, and treatment [13].

During the whole 20<sup>th</sup> century and for the 21<sup>st</sup> century the most frequent occurring causes for admission to CAP have been behaviour and conduct disorder and difficulties

with adaptation to school. The typical CAP patient is either “a troublesome 10-year-old boy” or “a depressed 14-year-old girl” [2, 11, 12, 14].

Descriptions of CAP emergency cases in the Stockholm region from 1970s and 1990s show that the six most common causes for emergency cases for boys were aggressive acting out behaviour, depression and suicide thoughts, family problems, acute reaction to stress, anxiety and suicide attempt. The six corresponding causes for girls are depression and suicide thoughts, suicide attempts, family problems, acute reaction to stress, and anxiety [15].

**GenP**, on the other hand, works with adult patients where the process of maturing has, if not ended, at least slowed down. This means that GenP psychiatrists working with adult patients can work with a system of classification of symptoms and states over time that is not as dependent on age and maturation. In CAP, great individual differences and gender differences appear which is why symptoms and behavioural disturbances can have varied meaning even in children of the same age. For instance, a certain symptom may be considered as an appropriate form of expression for children in a certain age, but be considered pathological in another age.

Despite differences in approach and methods of practice, it is obvious that there is a common group of CAP patients who later requires GenP care, especially patients diagnosed during child- or adulthood as suffering from schizophrenia, schizotypal disorder, delusional disorders and/or psychotic mood disorders.

To be able to answer questions about the transition between CAP and GenP field of knowledge and the outcome for children and adolescents cared for in CAP, and to reach optimized co-operation between the two disciplines both patient and population studies are required. A smaller county council and province study area, with clearly defined CAP respective GenP care, provides unique postulations to closer investigate and describe both current patient groups and the general population

This thesis is one in a row of various Swedish longitudinal studies trying to answer some of the questions addressed.

## **3 BACKGROUND**

### **3.1 PREVIOUS LONGITUDINAL STUDIES**

In Sweden, we can proudly note that there are prospective and longitudinal studies describing CAP patient materials in different time periods, from 1928 until present, and this may be considered to be unique in the research field. Researchers in the Nordic countries, especially in Finland, have also the opportunity to use registers that allow longitudinal studies of this kind. In the following sections different longitudinal studies from Sweden and some Nordic studies are reviewed.

#### **3.1.1 Descriptions of CAP patients**

CAP patients have been described from as early as 1928 when Alice Hellström started her description of psychopathic boys treated at the Mellansjö treatment home.

Alice Hellström described all the children who came to Mellansjö treatment home 1928-1940 under a special research protocol, which she established with the help of Bror Gadelius and Isak Jundell. She followed then her patients long time after her retirement and until 1968. However, because of age she was not capable of completing her report. The complete research material was bequeathed to the CAP clinic at the S:t Görans children's hospital in Stockholm, where Ingegärd Fried completed the work in her licentiate's dissertation [16]. Alice Hellström's own words when she was about sixty years grappling with its materials and the long observation period are worth considering: "It is about a child material which, although very different from today's, but to their essential constitutional reactions is the same human beings as today" [16].

The next study of children treated by child psychiatry was the longitudinal prospective follow up of 2,164 child and adolescent guidance clinic patients (cared for 1953-1955) followed up to 1975. This group was originally studied by Curman and the study was later completed by Nylander [11, 17]. The Stockholm population has been used as a comparison group in some of the papers included in this thesis.

#### **3.1.2 Different Swedish risk groups**

Various risk and control groups and children from the general population have been described with prospective longitudinal research from the perspective of several scientific disciplines (see Table 1). This provides a number of opportunities to discuss similarities and differences between patient groups, other groups at risk and children in general.

**Table 1. Different risk groups as described with longitudinal / prospective methodology.**

Sample	Discipline	Criminality	Alcoholism	Follow-up period
Psychopathic boys treated at the Mellansjö-treatment home	CAP	41%	28%	1928-1968 [16]
Delinquent boys treated at the Children's Village SKÅ	CAP	67%	58%	1954-1973 [18]
Young law-breakers from the general population	CAP, Sociology, Psychology, Criminology	39%	46%	1960-1972 [19]
Teenage alcoholics	CAP	42%	58%	1964-1985 1964-1977 [20]
Adopted children with heredity for social problems /alcoholism	CAP	14%	21%	1930-1972 [21]
Children of alcoholic fathers	CAP	42%	35%	1958-1978 [22]

In addition to the studies named above there are also descriptions of CAP patients conducted with so called cross section methods.

In 1950 chief physician Svante Nycander at the Erica Foundation presented his thesis "*Personlighetsutveckling på avvägar*" (Personality Astray) where 308 boys and girls that were examined and treated at the Erica Foundation Curative Pedagogy Institute in Stockholm were described [14].

Ulf Otto, at the University of Lund, used retrospective longitudinal methods in his thesis from 1972 "*Barns och ungdomars självmordshandlingar*" (Suicidal acts by children and adolescents) [23] to describe during a period of fifteen years the outcome for 1,727 boys and girls that at the end of the 1950s were treated for attempted suicide. The results of this study have been recovered also in later Swedish studies that indicates that children and youth's suicide acts are a "call for help" that needs treatment, support and help [23]. However, attempted suicide in itself may be a "poor" predictor for later executed suicide. The high risk group that commits suicide before the age of 25 seems to be found among those who develop psychiatric illness or anti sociality and addiction [12, 24].

During pre-puberty and puberty behaviour problems and mental symptoms are common among children in general. When 222 common Stockholm boys were described during the 1950s it appeared that every tenth boy in the age of 8-16 years had phobias and compulsive acts. The result of the description of symptoms showed that every fourth schoolboy suffered from some kind of difficulty, nervous symptom or difficulty in adapting to the extent that specialist help or special treatment was needed. However, their prognosis was not decided by the load of symptoms or the behavioural disturbances. The 18 year follow up assessment showed that the prognosis for most of

them was much better than was expected and it was not the load of symptoms but learning ability and home environment that was of importance for the future outcome [18].

### 3.1.3 Studies on the Swedish general population

In addition, different risk and control groups and the general population have been studied with prospective longitudinal research methods from various disciplines during the second half of the 20<sup>th</sup> century as shown in Table 2.

**Table 2. Different control groups and children from the general population as described with longitudinal / prospective methodology**

Sample	Discipline	Criminality	Alcoholism	Follow-up period
The Lundby-study	Psychiatry	8%	10%	1947-1987 1947-1972 [16, 25]
222 Stockholm boys	CAP	15%	19%	1954-1973 [18]
Controls/"social twins" to children of alcoholic fathers	CAP	25%	20%	1958-1978 [22]
The Metropolitan project	Sociology, Criminology	31%		1963-1979 [26, 27]
The Solna Study	Paediatrics, CAP	35%		1955-1988 [28, 29]
The IDA-project	Psychology	38%	17%	1965-1985 1965-1980 [30, 31]

The Lundby Study is a project exceptional and world leading by its prospective design [6]. International reviewers [32] have stated that “the Lundby Study has produced prevalence, incidence and outcome data on depression and anxiety over many years, and is one of the few studies capable of producing reliable data on changes in incidence” [33]. It is a well-known longitudinal survey of the mental health in a total Swedish population during the time period from July 1, 1947, to July 1, 1997. The Lundby population consisting of 3,563 probands was investigated in 1947, 1957, and 1972. Sufficient information was available for 98–99% of the subjects. In 1997–2000 Per Nettelbladt and his research team carried through a fourth field investigation.

In a longitudinal research project, Nylander and Rydelius [22] followed up the children of male alcoholics from the lowest social class. The results of these studies have shown that when they are still small, the children exhibit signs of mental disturbances and that when they become adults; the boys develop social maladjustment problems and addictions, and have a high rate of both somatic and psychiatric diseases. In comparison to their controls (matched for socio-economic class), the values found for these variables are consistently higher for the probands.

The Stockholm Metropolitan study is a follow-up of 15,000 individuals born in 1953 who were still living in the Stockholm Metropolitan area in 1963. The project was initiated by late professor Carl-Gunnar Janson and is now conducted by Sten-Åke Stenberg and Denny Vågerö [34]. The study was primarily concerned with sociological issues of social mobility and organization, conformity and deviance, and marital patterns. This study has resulted in over 100 publications [35].

The IDA project is a prospective, longitudinal research program led by Professor David Magnusson from the outset in 1965, investigating three cohorts of subjects: all boys and girls who attended school in a municipality in mid-Sweden, and attended the third, sixth or eighth grade at the time of the first data collection. The main group, encompassing in excess of 1,400 individuals, are the participants in most of the research conducted in the program [36].

The Solna study is a birth-to-maturity study of 212 children born in Stockholm in the mid 1950s. The goal was to acquire a comprehensive picture of individual growth and development by charting the course of physical and psychological development and obtaining reasonably comprehensive life histories that would be useful in many areas of research. The information covers many issues from birth to mid-life. The database is large [37].

#### **3.1.4 Studies in the Nordic countries**

Thomsen followed up a total of 546 children and adolescents in Denmark, aged 5 to 15 years. They were inpatients in psychiatric hospitals throughout Denmark between 1970 and 1973, and followed up regarding later readmissions and mortality. Approximately one-third of the sample had at least one readmission after the age of 18 years. In total, 24 probands died during the study period. Eight individuals had committed suicide. The SMR was significantly increased [38].

Thomsen also performed a register-based study of 485 children (0-15 years of age) admitted to a child psychiatric hospital from January 1, 1970, to December 31, 1972, who were followed up on December 31, 1986. They showed higher rates of admission to psychiatric hospitals in late adolescence or young adulthood than found in an age-standardized general population [39].

Psychiatric morbidity, expressed as hospital admissions during a 30-year follow-up period, among 322 former child psychiatric patients in a register investigation was studied by Larsen. They were admitted from 1949-1951, and were followed up as of December 31, 1980. By the variables employed, 37% of the sample were judged to have had a good overall outcome, with diagnosis being an inconsistent predictor of outcome [40, 41].

An epidemiological study of psychopathology in the first years of life and of the association between mental health problems in infancy and psychiatric disturbances later in life is investigated in a project studying mental health problems and possibilities of intervention from infancy and onward. This Danish study of a general population consists of a birth cohort of 6,090 children born in the year 2000 in the County of

Copenhagen, the Copenhagen County Child Cohort (CCCC 2000). Results from this study will add to the knowledge of risk factors and course of mental health problems in childhood and contribute to the validation of the mental health screening made by public health nurses [42].

A Norwegian population of 1,276 former adolescent psychiatric inpatients was followed up 15 to 33 years after hospitalization by Kjelsberg by record linkage to the national registers of criminality (n=932), disability benefits (n=1,095) and causes of death (n=1,095). In total, 1,095 patients (53.7% males), representing 85.8% of the original sample could be traced. At follow-up, 52.0% of those investigated had engaged in criminal activity. It was shown that male sex, psychoactive substance use disorder, short hospital stay and poor impulse control remained strong and independent predictors of death [43-47].

The Finnish “From a Boy to a Man study” has an objective to study associations between comorbid psychopathology and long-term outcomes in a large birth cohort sample from age 8 to early adulthood. The sample included long-term outcome data on 2,556 Finnish boys born in 1981 and the aim was to study the impact of early childhood psychopathology types and informant sources on young adult outcomes, based on data from a military registry of psychiatric diagnosis, a police registry on criminal and drug offences, and self-reported problems in late adolescence and early adulthood. The conclusions in this study were that the subjective suffering and long-term burden to society are especially high among children with comorbid conduct and internalizing problems in childhood. A major challenge for CAP, education, and social services is to develop effective intervention strategies focusing on these children [48].

In a population-based birth cohort in Finland, with the aim of studying the continuity of psychopathology from the age of 3-12 years, children’s emotional and behavioural problems were assessed at age 3 using the Child Behaviour Checklist 2-3, and at age 12 by parents using the Child Behaviour Checklist 11-18, and the Youth Self Report completed by the children. Behavioural ratings were obtained from 800 subjects at both time points and the results showed the complexity of pathways in psychopathology from early childhood to preadolescence. In particular, aggressive and destructive behaviour in very early childhood predicted later problems and require early recognition and possible intervention at an early age [49].

A Northern Finland 1966 birth cohort has been followed-up in different studies for 34 and 35 years regarding childhood precursors and risk factors of schizophrenia. The findings supported the longitudinal dimension and life span models of schizophrenia. No powerful risk factor, pre-morbid sign or a risk indicator was identified that was useful for the prediction of schizophrenia in the general population was identified [50-53].

## **3.2 RELATIONSHIPS BETWEEN MENTAL DISORDERS IN CHILDHOOD AND ADULTHOOD**

In his opening speech at the 26<sup>th</sup> Berzelius symposium “Mental and Psychosocial Adaptation in Children - A Longitudinal and prospective Approach” (Linköping, May 1993) sir professor Michael Rutter discussed today’s “current opinions” and level of attainment with 1960s and 1970s. This was an update of a lecture from 1972 about “Relationships between child and adult psychiatric disorders” [54, 55].

Rutter stated that when the relationship was reviewed over the two last decades [54] there was a paucity of evidence on the adult outcome of mental disorders among children and the childhood antecedents of mental disorder in adulthood; it was concluded that most links over time became rather uncertain or non-specific. When the same topic was reconsidered a dozen years later, there were a few more research findings but the empirical base had not expanded greatly. The findings were used to consider both the conceptual issues and possible mediating mechanisms [55].

There is mounting evidence that many, if not most, lifetime psychiatric disorders' first appears in childhood or adolescence and that childhood maltreatment strongly predicts poor psychiatric and physical health outcomes in adulthood [56, 57].

Most adult disorders should be reframed as extensions of juvenile disorders. In particular, juvenile conduct disorder is a priority prevention target for reducing psychiatric disorder in the adult population [58].

Findings from British birth cohort studies indicate that social factors operating during childhood such as parental social class at birth and school educational performance are related to adult disease risk [59].

### **3.2.1 Affective disorders**

Although, there has been a radical change over the last 1-2 decades in the understanding of depressive disorders arising early in life, Swedish longitudinal studies indicate that psychotic mood disorders are rare among CAP patients [17]. Standardized methods of diagnostic assessment began to show that clinical conditions with phenomena quite similar to those seen with affective disorders in adult life were much more common in childhood and adolescence than had been hitherto appreciated. The scepticism that had dominated thinking about childhood depression for many years had in the 1990s been replaced by a huge upsurge of clinical and research interest in these disorders [55]. The seriousness of the condition has been underlined by the substantial suicide risk [60].

Adolescent depression carries an elevated risk of adult depression irrespective of comorbidity. Comorbid conduct disorder in childhood is associated with elevated rates of other psychiatric outcomes [61]. Ferguson and colleagues found that young people having early depression were at increased risk of a later adverse psychosocial outcome. There was a direct linkage in which early depression was associated with increased risk of later major depression and anxiety disorders. Linkages between early depression and

other negative psychiatric outcomes appeared to reflect the effects of confounding factors [62]. Harrington and his colleagues found that depression in childhood or adolescence was associated with a fourfold increase, compared with a non depressed psychiatric group, in the risk of recurrence of major depressive disorder during early adult life. Even more important was the finding that the childhood depression group did not show any increased risk for any mental disorder other than affective conditions [63].

Early risk factors for affective disorder exert effects by modifying person-environment relationships close to onset of adult symptoms. Sensitivity to life events may be transmitted from parents to offspring; psycho pathological continuity over the life-span may be explained in part by continuity of altered stress sensitivity [64].

Roza and colleagues suggest different developmental pathways for mood and anxiety disorders. Anxiety disorders predominantly began in childhood and early adolescence whereas the incidence of mood disorders increased sharply in adolescence and young adulthood. A follow-up showed that mood disorders were predicted by high scores on the anxious / depressed scale and on the internalizing composite (withdrawn somatic complaints, and anxious / depressed). Anxiety disorders were significantly predicted by the social problems scale and the externalizing composite (delinquent behaviour and aggressive behaviour). The predictions based on problem behaviour remained stable during a 14-year period across adolescence and young adulthood [65].

### **3.2.2 Anxiety and obsessional disorders**

Much less is known about the adult outcome of anxiety disorders [55]. Childhood antecedents of anxiety disorders in adulthood remain poorly understood. Behavioural inhibition is an identifiable early childhood predictor of later anxiety disorders [66].

Until relatively recently, obsessional conditions tended to be classified with anxiety disorders, but the evidence from systematic studies led to an appreciation that they constituted a rather different type of condition. Both medium- and long term follow-up studies have shown a high persistence of obsessional symptoms. Characteristically, however, there tends to be a fluctuating course, often with limited improvement [55].

Early exposure to serious trauma, specifically childhood sexual assault, may lead to a different clinical presentation in GAD patients [67]. High levels of lifetime exposure to adversity are causally implicated in the onset of depressive and anxiety disorders [68]. Childhood separation anxiety disorder may be a risk factor for multiple anxiety syndromes in adulthood [69].

Findings by Woodward and Ferguson suggest that adolescents with anxiety disorders are at an increased risk of subsequent anxiety, depression, illicit drug dependence, and educational underachievement as young adults [70].

### **3.2.3 Eating disorders**

Many follow up studies have provided a fairly consistent broad picture of the long-term outcome of anorexia nervosa. In about half the cases, eating behaviour returns to normal with restoration of weight and normalization of menstruation [55]. The presence of eating problems in early childhood or an eating disorder in adolescence confers a strong risk for an eating disorder in young adulthood [71]. Childhood adversities may also contribute to greater risk for the development of eating disorders and problems with eating and weight that persists into early adulthood. Maladaptive paternal behaviour may play a particularly important role in the development of eating disorders in offspring [72].

### **3.2.4 Conduct and hyperkinetic disorders**

In many ways the field has opened up most concerning the adult outcome of conduct disorders in childhood. The strong continuities with personality disorder in adult life have been adequately confirmed but the picture has been modified in two key ways. First, it has been shown that the adult outcome (especially in females) extends well beyond antisocial personality disorder to include a broader group of personality disabilities and to increased vulnerability to a range of acute mental disorders. One of the major advances in the last two decades has concerned the differentiation between hyperkinetic and conduct disorders and a much more improved definition of the former [55].

The second way in which the picture has been modified is that serious questions have been raised on the mechanisms involved. Because the persistence over time has been so strong, there has been a tendency to presume that it must reflect an unchanging constitutional trait or disorder. Sometimes this may be the case, but the genetic component in antisocial behaviour as a whole is quite modest [55].

Nevertheless, although findings suggest that indicators of ADHD are already present in early life, there are more difficulties diagnosing ADHD in pre-school children than is the case with school-age children [73].

It seems that later antisocial behaviour largely depends on the earlier occurrence of conduct problems whereas scholastic attainment in adolescence is a function of earlier hyperactivity [55]. Childhood conduct problems are associated with a wide range of an adverse psychosocial outcome (crime, substance use, mental health, sexual / partner relationships) [74]. A poor adult outcome is most likely in the case of conduct disturbance that is of a particularly early onset (in childhood) and is also associated with hyperactivity/attention deficits and poor peer relations. Further, it is evident that the poor outcome is a function of persistent pervasive conduct disturbances in childhood rather than transient or isolated antisocial problems [55].

Numerous studies have shown that heightened frequency of ADHD is associated with comorbid oppositional / defiant behaviour and conduct problems in childhood. To an important extent this derives from a shared genetic origin but it is uncertain whether or not this constitutes the only mediating mechanism. Follow-up studies have shown that

ADHD predicts later antisocial behaviour, but that the reverse predictive relationship has not been found. Nevertheless, there must be caution in drawing causal inferences from this difference because it could simply reflect the usual age of first manifestation of the two types of behaviour.

ADHD, like the other neurodevelopmental disorders, is said to be strongly influenced by genetic factors and shows a marked male preponderance, is associated with specific and general cognitive deficits, and is presumed to have its origins in some form of a cognitive processing deficit or bias. It seems that the main problem lies in behavioural deregulation, executive deficits in inhibitory control and working memory, and delay aversion [73].

The follow-up of clinic samples of children with ADHD into adolescence and adult life has led to several important findings [75, 76]. First, adult psychopathology (especially antisocial personality disorder and substance abuse) is more frequent among individuals with ADHD than in comparison samples of young people without childhood psychopathology [73].

Second, although good data are lacking regarding the extent to which the adult psychopathological outcome is worse for ADHD than other forms of mental disorder in childhood, the findings show that childhood ADHD is the precursor of later antisocial disorder, even in the absence of co-occurring oppositional defiant or conduct disorder symptoms in childhood [77]. Prognosis is less advantageous, however, for individuals with hyperactivity at school or at both school and home than it is for those with hyperactivity only in the home setting [78]. It is also less advantageous for those who already have associated conduct problems in childhood.

Third, if the standard diagnostic criteria for ADHD are used in adult life, there is a marked drop between adolescence and adulthood in the proportion of individuals who had ADHD in childhood who continue to meet the same diagnostic criteria in adult life [73].

Fourth, both the genetic and epidemiological findings indicate that ADHD feature mainly function dimensionally, rather than categorically [73].

Fifth although the validity of differentiation among sub-varieties of ADHD lacks a solid empirical base, the evidence suggests that there is valid heterogeneity [73].

Sixth, although the rate of psychopathological, social, and educational impairment in adult life for individuals diagnosed with ADHD in childhood is substantially increased, it is still the case that there is considerable individual variation in outcome and at least half appear to be reasonably well functioning in adult life [73].

Rutter stated that in seeking an understanding of the factors that mediate both the continuities and the discontinuities over time and also the individual differences in developmental course; it will be necessary to consider the likely importance of both genetic mediators and gene–environment interactions [73].

### 3.2.5 Schizophrenia

On the whole, the findings on the long-term course of schizophrenia beginning in childhood are broadly similar to that of schizophrenia beginning in adult life. In both cases, the disorder is usually fluctuating with each episode often marked by prodromal, active and recuperative phases, followed by quiescent or residual deficit periods. Like the earlier studies of special groups, the general population prospective studies have confirmed that overt schizophrenia in adulthood is frequently preceded by socio-emotional behavioural disturbance [73]. The long-term course of childhood and adolescent onset schizophrenia is worse than in adulthood schizophrenia, and the patients with manifestation of the disorder below the age of 14 have a very poor prognosis [79].

Nevertheless, early case-control and follow-back studies [80] showed that children who later developed overt schizophrenia were more likely than controls to show social, emotional and behavioural problems in childhood [73]. Various behaviours, in particular, withdrawn and delinquent-aggressive behaviour in adolescents at risk of schizophrenia may predict a later onset of the illness. These behaviours, however, are far less predictive of isolated psychotic symptoms prior to a psychosis onset [81]. Schizophrenia-related psychoses can be followed back to early behavioural disturbances [82]. Conduct Disorder is a distinct comorbid disorder that runs parallel to the course of schizophrenia [83]. Early neuroticism may be a precursor to the onset of psychotic symptoms. The mechanisms underlying this association are unclear, but may relate to overlapping features between prodromal phases of psychosis and items that measure neuroticism [84].

Total population epidemiological and longitudinal studies provided a stronger test of the suggestion that abnormalities in childhood constituted precursors of schizophrenia that did not become manifest until early adult life. The precursors include delays in early motor development and impairments in receptive language and cognitive functioning [73].

Findings on CAP clinic attendees who go on to develop either schizophrenia or bipolar disorder, nevertheless, suggests that there may be a degree of diagnostic specificity, with abnormal suspiciousness / sensitivity and relationship difficulties with peers being particularly associated with later schizophrenia [85].

Three main queries have yet to be resolved concerning the meaning of the findings on the features in childhood and adolescence that predict the later development of a schizophrenic psychosis. Accordingly, this necessarily raises queries about what is meant by a prodromal phase. Second, all the findings raise the question of what it is that leads to the translation of precursors or prodromata into overt schizophrenia. The final query concerns the possibility that, despite the early neurodevelopmental abnormalities, there are further changes in both cognitive function and brain structure and function that take place during the course of the schizophrenia spectrum disorder in adult life either as a result of the disease process or of the drugs used in its treatment [73].

### **3.2.6 Personality disorders**

In the empirical literature, there is support for the idea of a relationship between childhood trauma and various psycho-physiological as well as pain disorders, and between borderline personality symptomatology and somatic preoccupation, as well as chronic pain [86]. Childhood disruptive behaviour has powerful long-term effects on adult antisocial outcomes, which continue into middle adulthood [87]. Personality disorders may represent alternative pathways of continuity for major depressive disorder and other Axis I disorders across the child-adult transition [88].

## **3.3 THEORETICAL FRAMES AND ELEMENTS**

Explanation for the origin and cause of psychiatric problems as well as their treatment and perception of those having mental illness has varied over time. Deviant behaviour and mental illness have been viewed from different philosophical, religious and theoretical perspectives throughout history. As heterogeneous these explanations are and taking into account all the differences within the activities and patient groups it is a delicate task to give a theoretical frame for psychiatry and psychiatric work. With all necessity this is only a quick glimpse of all the theories that may be given within the scope of this thesis, in particular since my studies are principally descriptive in their design.

### **3.3.1 Theoretical frames**

Each theory is culture bound, and reflects the thinking in a given epoch and any theory of individual and interaction level reflects a certain outlook on people within the corresponding perspective of the discipline in which it was developed [89].

It appears that GenP research and practices since the mid 1800s are primarily of biological nature. Science took the central role in place of religion. However, psychiatric activities have a multi-theoretical background whereas roots of theoretical development within child psychiatry can perhaps be more differentiated from paediatrics, pedagogic, psychology sociology and social work.

It took well into the mid 1900s before CAP developed into an independent medical discipline. During the 1930s and 1940s it was discussed whether the issues of CAP were reflective of social welfare or medical service. A parliamentary resolution in 1944 established CAP as a medical speciality [90].

Swedish CAP developed over 50 years from 1900-1950 and with the roots in paediatrics, education/school psychiatry, child social welfare and psychiatry to a discipline of its own. A multidisciplinary comprehensive and eclectic and empirically based model was developed on how to understand psychopathology in growing children and youth. This model included the child itself and the following factors: sex; constitution (the genetic inheritance and factors affecting the foetal life and during delivery); chronological age versus maturation / developmental / functional age; handicaps and diseases It included environmental factors from the home (heredity, psychiatric status and caring capacity of parents, attachment, economy) from the school (peers and learning capacity) and society (dwelling, social class etc.) and to these

factors, factors were added related to traumatic experiences and if the demands put on the child did fit or not fit the child's own capacity. With this model [91] the way to assess why a child was having behavioural, cognitive and/or emotional problems include the following nine steps:

- Careful history.
- Validation of the history.
- Somatic investigation including neurology, laboratory tests, chromosomes, X-ray, vision and hearing.
- Psychological investigations.
  - Psychometric assessments
  - Projective tests.
- Social evaluations.
- Educational assessments.
- Psychiatric assessments of both the child and the parents.
- Observation in different settings.
- A multidisciplinary diagnosis.

Over the years, and independent of other theories described in the following, this has served as a basis for CAP research.

The theories can be divided into different categories with different starting points. Both Cederblad and Wrangsjö have used a division into different levels, from individual to structural types [89, 92].

In her book "Child and Adolescent Psychiatry" [92] Marianne Cederblad reports a number of theories to use in CAP work. Symptoms occur in almost all cases as a result of a combination of different factors in children's life memories and images from past life as well as hereditary factors according to Cederblad. She distinguishes between structural, interpersonal and intra psychic factors that interact with genetic heritage.

Björn Wrangsjö has analysed and discussed the theory formation in psychiatric activities. Wrangsjö categorizes theories of different types: the individual (this includes medical / biological respectively individual psychological approach) the group focused and structurally oriented (simplified affecting the relations with and between the social system) [89]. A classification in line with Urie Bronfenbrenner's psychological developmental theory, the Ecological Systems Theory, also called "Development in Context" or "Human Ecology" that aimed to explain how individual factors of a child and the child's environment affects how a child grows and develops [93].

Each theory relates to certain aspects of a system at a certain level and its range appears to some extent by how many of these system aspects cover [89].

Another distinction can be made within various fields of knowledge used to explain the causes of and mechanisms involved in mental diseases. A single theory can rarely alone explain this; mental illness is often a result of the interaction of multiple causal factors noted above [8].

The words' *explanation* and *understanding* used in clinical work also belongs to various frames of reference. The word explanation belongs to a scientific frame of reference and is linked to a linear cause and effect thinking. Understanding belongs to a human or social science frame of reference in case an idea or understanding of a phenomenon is the intention [89].

Theories mostly targeted to the individual are the biological and medical theories and most of the psychological theories.

### **3.3.2 Biological and medical theories**

Genetics and epigenetic, neuropsychiatry, evolutionary psychology and socio-biology are biological and medical theories used. They are all primarily targeted to the individual. Genetic psychology is the study of the influence of genetic factors on personality development. Neuropsychiatry is the branch of medicine dealing with mental disorders attributable to diseases of the nervous system.

Evolutionary psychology attempts to explain mental and psychological traits'—such as memory, perception, or language—as adaptations, that is, as the functional products of the natural selection or sexual selection. Evolutionary psychologists argue that much of human behaviour is generated by psychological adaptations that evolved to solve recurrent problems in human ancestral environments [94].

### **3.3.3 Psychological theories**

Most psychological theories are based on the individual and the intra psychic factors and some of them interpersonal, starting in infancy and young ages with developmental psychology.

At the 16<sup>th</sup> IACAPAP World Congress in Berlin, August 22–26, 2004 professor Helmut Remschmidt gave the Donald Cohen Lecture on “The place of development in child and adolescent psychiatry.” Remschmidt stated four scientific milestones in the progress of developmental psychology. The principle of self-regulation in human development (Jean Piaget), the concept of social learning in human development (L. S. Vygotsky), the concept of socioemotional development or attachment theory (John Bowlby, Mary Ainsworth) and the concept of life-span development (Baltes, Rees and Nesselroade [95]).

The attachment theory formulated by John Bowlby [96] and further developed by, among others Mary Ainsworth and Patricia Crittenden emanate from psychoanalytic theory, more specifically, object relations theory. Object relations theory describes the dynamic process of developing a mind as you grow up in relation with real others in the environment. Attachment theory is today one of the most psychodynamic development theories used.

The formulation of the psychoanalytic development theoretical frame started with Sigmund Freud and his well-known drive theory. His daughter Anna Freud represents the ego psychology, a precursor to the object relations theory. The fourth and the fifth wave of the psycho-dynamic developmental psychology are the theory formulated by

Daniel Stern about the sense of self and the psychology of affect and script formulated by Silvan Tomkins and Donald Natanson [97].

Besides the psychoanalytic theory, that has been dominant a long time among the psychological theories, cognitive theory and behaviourism are theories that have had a great impact on psychiatry. Cognitive psychology is a branch of psychology that investigates internal mental processes such as problem solving, memory, and language. In addition to the concepts put forth by Jean Piaget it had its foundations in the Gestalt psychology. A dysfunctional approach is often characterized by negative thoughts and feelings.

Behaviourism puts its emphasis on experimental methods, focuses on variables we can observe, measure, and manipulate, and avoids whatever is subjective, internal, and unavailable [98]. Ivan Pavlov, John Watson and B.F. Skinner are the three most known behaviourists.

In the treatment context cognitive theory and behaviourism serve as a theoretical foundation for Cognitive behavioural therapy, a psychotherapeutic approach and an umbrella term for a number of psychological techniques that during the last decades has been successful in psychiatric treatment.

The social cognitive theory formulated by Albert Bandura who is by some considered a “father” of the cognitive movement, explains how people acquire and maintain certain behavioural patterns, while also providing the basis for intervention strategies. One central concept is reciprocal determinism which simply means that the world and a person’s behaviour cause each other. Other important concepts are observational learning, or modelling and self-regulation [99].

Another theory that has broad application to the work with people in various activities is the humanistic psychology with Abraham Maslow and Carl Rogers being some of the main representatives. Humanistic psychology is a value orientation that holds a hopeful, constructive view of human beings and of their substantial capacity to be self-determining [100].

### **3.3.4 Theories on groups and families**

The group focused theories are mostly useful in treatment situations, group therapy and family therapy. Different groups may be educational groups, pedagogical groups, workshops, psychosocial and therapeutic groups. They can be formed as large groups (about forty to hundreds of group participants), median groups (twelve to forty participants), and small groups (five to ten participants), and as well as time-limited groups called short-term groups.

Family therapy theories have also been used as diagnostic and assessment instruments looking at the problems for the individual. Family therapy, also referred to as couple and family therapy and family systems therapy, is a branch of psychotherapy that works with families and couples in intimate relationships to nurture change and development. As the field has evolved, the concept of the family is more commonly

defined in terms of strongly supportive, long-term roles and relationships between people who may or may not be related by blood. Family therapy has been used effectively in the full range of human dilemmas; there is no category of relationship or psychological problem that has not been addressed with this approach [101].

However, theory is not always prominent when family therapy is described. Ninety-five studies from the journals *Family Process* and *Journal of Marital and Family Therapy* were evaluated regarding their use of theory. While a majority of the articles were judged to use theory in either an explicit or an implicit manner 42% did not appear to draw on theory in either the introductory or discussion sections [102].

There are many different family therapy methods and some of them are Intergenerational Family Therapy or Bowen-Intergenerational Theory, The Structural approach to Family Therapy, developed by Salvador Minuchin, Strategic Family Therapy, sometimes known as Problem Solving Therapy, primarily associated with Jay Haley and Cloe Madanes, Systemic Family Therapy, sometimes identified as the Milan Model, Communications / Experimental Family therapy include the work of the two pioneers Virginia Satir and Carl Whitaker, Narrative Therapy associated with Micael White that emphasizes the construction of meaning as a central theme of therapy, and Solution Focused Therapy that focuses on what clients want to achieve through therapy rather than on the problem(s) that made them to seek help.

Important recent developments are the concept of reflexivity where the observer is part of the system being observed. Family relationships are a principal source of mental health and psychopathology for individuals [101].

Finally, The Ecological Systems Theory, formulated by Urie Bronfenbrenner, defines complex “layers” of environment each having an effect on a child’s development and it moves from the small (micro) to the structural level (macro) [93, 103].

## 4 AIMS

An overall aim of this thesis was to throw light upon several important questions concerning the CAP patient group. Were their difficulties a question of mental illness, disablement or behaviour disorders? What happened to former CAP patients? Did they become well functioning adults?

These questions were further operationalized. Did the former CAP patients show early signs of severe psychiatric illness and who developed psychotic symptoms and illness? How many were at risk for committing suicide? How many were convicted of offences?

A final question was, who were the patients in need of psychiatric care without a previous contact with CAP and how did they differ from the former CAP group?

### **Specific aim of included papers:**

- I: Two questions were addressed in this study. Do Swedish CAP patients continue to risk premature death - despite overall health improvement that has occurred in Sweden? If so, what kind of information can predict later suicide? (*Paper I*).
- II: This study investigated the risk for CAP patients to have criminal records. The study's hypothesis was that children, who were identified by CAP units as having behavioural and school problems and dysfunctional families, were at high risk to become criminals (*Paper II*).
- III: The goal in this study was to obtain answers to a number of questions concerning a group of former CAP patients diagnosed during child- or adulthood as suffering from schizophrenia, schizotypal disorder, delusional disorders and/or psychotic mood disorders: At what age was the diagnosis made? Was this diagnosis later changed and, if so, in what manner? Were early signs of the disorder detectable prior to or at the time of admission to CAP care? Which CAP patients were later diagnosed as psychotic in GenP? How did this latter group differ from those who had already received a diagnosis before the age of 18 years? (*Paper III*).
- IV: The aims in this study were to answer the following questions. Who were the patients in need of psychiatric care without a previous contact with CAP? Did the frequency of and the seriousness of their need of psychiatric care differs from the former CAP group? Which were the needs for hospital care during childhood and youth for this group without previous contact with CAP and the former CAP-patients? (*Paper IV*).

## **5 DESIGN**

### **5.1 DESIGN OF THE TWO STUDIES**

#### **5.1.1 The CAP patient group**

This thesis was conducted to answer several important questions concerning the CAP patient group and mainly the question what happened to former CAP patients in adulthood in different aspects. The homogeneity of the psychiatric care organization in the study area, the responsive study populations, the possibility of studying hospital records and the unique opportunity to use National registers allowed for the potential to carry out a longitudinal study, descriptive in its nature. Data are quantitative and analysed with well-recognized statistical methods.

Initially three studies were performed based on a total sample of former CAP patients' first followed up to 1999 and finally up to and including December 31, 2002. Three examination fields were the foundation for Paper I-III, mortality and suicide, crime, and psychotic disorders.

It was also possible to use a previous Swedish follow up study for comparisons, a sample of 2,164 patients from Municipal Child Guidance Clinics in Stockholm (see Table 4) who were treated between 1953 and 1955 and followed over 20 years. Further when possible comparisons were also made to the general Swedish population.

#### **5.1.2 GenP patients with no previous psychiatric care**

The former CAP patients only constituted a smaller part of the GenP patient population. Therefore, a second retrospective study was performed comparing GenP patients with and without previous CAP care in childhood and adolescence. Baseline was set in adulthood psychiatric inpatient care and the incidence of medical care in childhood and adolescence was examined.

#### **5.1.3 Follow-up periods**

The group of CAP-patients (*Paper I-III*) was followed from finalized CAP-care 1975-1990 and up to 2003. They had been admitted for inpatient or outpatient CAP treatment in Jämtland County during 1970–1990. Some of the youngest patients may have been readmitted to CAP care after 1990. The follow-up periods are shown in Table 3.

**Table 3. Follow-up periods for the index group in paper I-III**

	Years between first visit at CAP and 2002-12-31		Years between finalized contact with CAP and 2002-12-31	
	All patients, n = 1,400	Deceased patients excluded, n = 1,361	All patients, n = 1,399	Deceased patients excluded, n = 1,360
Mean value	22.2	22.5	20.2	20.5
S.D	5.5	5.3	5.2	4.9
Min.	0.6	12.0	0.0	28.0
Max.	33.0	33.0	28.0	12.0
Median value	22.7	22.8	20.3	20.6

The two groups investigated for somatic hospital care (described in *Paper IV*) was followed until and including December 31, 1999, or until they reached the ages of 23-42 years.

## 6 MATERIAL

### 6.1 INDEX GROUP PAPER I-III

The index group comprises 1,400 former CAP patients, including 285 in- and 1,115 outpatients, or 98.6% of the original population. All 1,420 patients born between 1957 and 1976 and admitted to in- or outpatient CAP care in Jämtland County, Sweden, during of the period 1975-1990 were initially considered for inclusion. Eight individuals not covered by the national registries and twelve who subsequently emigrated during the follows-up period were excluded. The age groups were chosen on the basis of the fact that the oldest patients, born 1957 may have finalized their contact at CAP just before they turned 18 years; that is 1975. The youngest patients, those born 1976, may have made their first visit at CAP during their first year of life but may also have been readmitted later than 1990.

### 6.2 COMPARISON GROUP PAPER I-III

In Table 4 the number of patients not included in the final samples from the comparison group (the Stockholm study) [17] and the corresponding group from Jämtland, and the reasons for the exclusion of these patients are listed as well as the distribution of those assessed in a 20 year follow-up after their CAP care and the distribution of gender.

**Table 4. Index groups for the Stockholm and Jämtland studies**

	Stockholm		Jämtland	
	Number	Percent	Number	Percent
Primary Material	2364		1420	
Excluded:				
Emigrated	100	4,2	12	0,8
Deceased during follow up	50	2,1	38	2,7
Unusable data	50	2,1	8	0,6
Inpatient care	0	0	270	19
Less than 20 year follow up	0	0	484	34,1
Index group:	2164	91,5	608	42,8
Males	1417	65,5	325	53,5
Females	747	34,5	283	46,5

### 6.3 INDEX GROUP PAPER IV

The index group (or the Non-CAP-group) consists of a sample of 167 inpatient or outpatient GenP patients at the Östersund hospital born the fifteenth day each month between the years 1957 and 1976 that have not been treated at any psychiatric unit in childhood and adolescence.

## 6.4 COMPARISON GROUP PAPER IV

A group of 487 GenP patients born between 1957 and 1976 who were treated at GenP at the Östersund hospital no later than 1999 and who had a previous psychiatric care period in childhood or adolescence constitutes a comparison group to the Non-CAP-group. In some aspects the Non-CAP-group also has been compared to the Swedish general population when possible.

## 6.5 THE STUDY AREA



Jämtland County is one of Sweden's 21 counties. It consists of the two provinces Härjedalen and Jämtland and minor parts of Ångermanland and Hälsingland. Jämtland is located in the western part of middle Sweden at the border to Norway. It represents 12% of Sweden's total land mass but only 1.5% of the population.

From 1975 – 2003, the total population varied from 133,433 to 127,645 with a peak of 136,301 inhabitants in 1994.

Östersund is the only city in the county and the city is a major trade centre for the entire county.

The county and the regional hospital in Östersund were well suited for this type of study. In Jämtland County there were one CAP clinic and one GenP clinic under the same health organization giving service to the whole population. Both clinics were located in the same hospital organization at Östersund Hospital.

## 6.6 SWEDISH REGISTERS

Sweden and the Nordic countries, especially Finland is unique concerning official registers. In this thesis several Swedish national registers were used. The parish registration required by the 1686 Church Ordinance laid the groundwork for future population statistics. Sweden began to keep population statistics in 1749, quite a unique phenomenon.

*National registration* is the fundamental registration of the Swedish population. In the national registration it is continuously registered who is living in the country and where they live. The register is based on personal identification numbers. For a long time it was conducted by the church through parish registration, but since July 1, 1991, the Swedish Tax Authority is responsible for the national registration [104]. Information from National registration; i.e. personal identification was used as a base for gathering information from all other official registers, which are described below.

From 1987 *the National Patient Register* covers all public inpatient care in Sweden. Statistics of diseases and surgical treatments of patients have a long history in Sweden. Data of this kind has been published for more than 100 years and was available during

the entire 20<sup>th</sup> century. In the 1960s the National Board of Health and Welfare started to collect data on individual patients who had been treated as inpatients at public hospitals. The register built up at that time initially covered all patients treated in psychiatric care and around 16% of patients in somatic care, involving six of the 26 county councils in Sweden [105]. This register has been used to collect data pertaining to inpatient psychiatric care and diagnoses (*Paper I-IV*).

*The National Causes of Death Register* has been used (*Paper I*) to establish time for death and causes of death. Along with the register death certificates have been examined. The National Causes of Death Register goes back to 1749 when a nationwide report system first was introduced. The National Causes of Death Register is annually updated and based on personal identification numbers and includes all death certificates for the Swedish population. The National Swedish Board of Health and Welfare has been responsible for publication since 1994 [106].

Statistics of persons convicted of offences has continuously been recorded since 1972 by SCB. The Swedish NCCP (BRÅ) is since July 1, 1994, responsible for Sweden's official crime statistics. *The Register of Persons Convicted of Offences* has been used to obtain information regarding criminality (*Paper II*).

## 7 METHODS

### 7.1 DATA COLLECTION

#### 7.1.1 Baseline for the follow-up study of former CAP patients

The study started in the mid 1990s when the first index group (*Paper I-III*) was identified through an examination of registration books and hospital records at CAP.

The personal identification numbers were checked and information about place of current residence was obtained at Local Tax authorities. Information about a number of patients (75) could not be found at first due to incorrect or incomplete personal identification numbers and their information was searched and checked in birth records at the regional state archives.

When the first index group (*Paper I-III*) was identified the hospital records at CAP were reassessed according to a protocol (based on previous empirical results from follow-ups of CAP patients).

The protocol entailed recording the following information from the CAP hospital records:

- Age at first admission to CAP and age at finishing the CAP care and gender.
- Who referred the patient to CAP?
- Where or with whom they lived with during period of CAP care (family, foster family, institution, etc.).
- Problems with learning and/or behaviour problems at school.
- Information about inpatient or outpatient care at CAP.
- At the time of admission to a CAP unit, family circumstances. If the patient's biological parents were living together, this would be described as a complete family and if not, as a split family.
- Any information about adoption.
- Reason for admission to CAP according to standards established by the Swedish Association for CAP.
- Diagnosis.

One-third of the outpatients were not given a formal diagnosis. Outpatients in the CAP unit did not receive diagnoses when their problems were considered temporary due to growing and maturation.

The retrospective data from CAP hospital records were used as independent variables to the dependent variables *deceased* or *alive*, *suicide* or *not suicide* (*Paper I*), *convicted of offences* or *not* (*Paper II*) and *psychotic disorder* or *not* (*Paper III*). Data was also used for the subgroup of patients used as a comparison group in Paper IV.

### 7.1.2 Distribution of baseline information

- The gender distribution was 733 female (52.4%) and 667 male (47.6%).
- Mean age at admission was 12.1 years of age (S.D. 4.0).
- The patients were referred to CAP by paediatricians or general practitioners (35%), by school or childcare personnel (22%), by social services (12%) or other authorities (2%) or else they by themselves and/or their parents sought help (29%).
- Inpatient care was given to 285 persons (20.4%).
- Over half of the index group (52.5%) lived in a split family.
- Nearly half of the patients (46.5%) had school problems noted in their records.
- The most frequent occurring reasons for admission to CAP are shown in Table 5 and diagnoses made at CAP are shown in Table 6.

**Table 5. The ten most frequent occurring reasons for admission to CAP, n = 1389**

Reason for admission to CAP	Frequency	Percentage
Behavioural disorder	292	21.0
Relationship problems	258	18.6
Anxiety	181	13.0
Somatic problems and eating disorders	138	9.9
Mental retardation and developmental problems	80	5.8
Suicide attempt, suicide thoughts	71	5.1
Depression	60	4.3
Reaction to stress	52	3.7
Enuresis or encopresis	47	3.4
Abused and/or neglected	38	2.7

**Table 6. Diagnoses (blocks) made at CAP according to ICD-10, n = 901**

Diagnoses (block)	Frequency	Percentage
Z00-Z99 Factors influencing health status and contact with health services	321	35.6
F90-F98 Behavioural and emotional disorders with onset usually occurring in childhood and adolescence	196	21.8
F40-F48 Neurotic, stress-related and somatoform disorders	140	15.5
X60-X84 Intentional self-harm	48	5.3
F50-F59 Behavioural syndromes associated with physiological disturbances and physical factors	46	5.1
F80-F89 Disorders of psychological development	39	4.3
F30-F39 Mood [affective] disorders	31	3.4
F70-F79 Mental retardation	27	3.0
F10-F19 Mental and behavioural disorders due to psychoactive substance use	24	2.7
F20-F29 Schizophrenia, schizotypal and delusional disorders	20	2.2
F60-F69 Disorders of adult personality and behaviour	4	0.4
Other diagnoses	4	0.4
F99 Unspecified mental disorder	1	0.1

### 7.1.3 GenP care

Considering the description of the CAP patients, a prospective survey was then made to examine the number of patients that were later referred to GenP care before 1999.

After receiving necessary permissions and ethical approval the collection of data continued with an examination of hospital records at GenP and linkage to the nationwide National Patient Register, the group of patients that had so far been treated in CAP and/or GenP, were identified. Information about GenP care was available from out- and inpatient care records in Jämtland County but only from inpatient GenP care in the rest of Sweden. This procedure was 2003 reduplicated to prolong the follow-up period.

From hospital records and register the following information was noted about GenP care:

- Age at first admission to GenP and age at last contact and gender
- Information about inpatient care or outpatient care (outpatient care only in Jämtland)
- Diagnosis. (The last made major diagnosis or the most frequent occurring diagnoses if different diagnoses occurred)

This was shown by the information collected:

- A third of the index group (37.9%) was admitted to GenP care,
- More female (62.3%) than male (37.7%) were later admitted to GenP
- Mean age at first admission was 22.2 years of age (S.D. 5.2).
- More than half (56.5%) were inpatients at GenP.
- A majority were admitted to GenP in Jämtland alone 81%, or in Jämtland and another county (10.7%) while only 8.3% were admitted to GenP in another county and not in Jämtland.

### 7.1.4 Information on mortality and suicide

The observed number of deaths and the causes of death (*Paper I*) were obtained from The National Causes of Death Register (The National Board of Health and Welfare and Statistics Sweden). Regional differences appear in the Swedish suicide rate. From 1980 to 1996, suicide rates were higher in Swedish metropolitan areas and in some regions including Jämtland County [107], compared to other parts of Sweden. Causes of death were classified as per the English version of ICD. This procedure was repeated on two occasions, in 1999 and in 2003.

### 7.1.5 Information on crime

Information on crimes (*Paper II*) was obtained from the NCCP database (the Register of Persons Convicted of Offences) where results for each person were displayed in three rows, which indicated if the person (1) was found guilty in a county court; (2) had received a fine issued by a prosecutor; and/or (3) had received a waiver of prosecution issued by a prosecutor [108]. A maximum of ten previous violations of a law was

displayed in the first search. If a person had more than ten convictions, this would be noted. Only the main crime was noted. Sometimes up to 19 types of offences are committed at the same time, but here, only the most serious crime could be registered, that is, the “main” crime. This procedure was also repeated on two occasions.

#### **7.1.6 Information on psychotic disorders**

A specific re-examination of CAP hospital records for those having a psychosis diagnosis either at CAP and or in GenP was performed in 2007 (*Paper III*). The records were evaluated using CAARMS described by Yung et al. [109], in which any possible early signs of psychosis were noted. The instrument has two functions: to assess psychopathology thought to indicate imminent development of a first-episode psychotic disorder; and to determine if an individual meets criteria for being at UHR for onset of first psychotic disorder.

#### **7.1.7 Information on medical treatment in childhood other than psychiatric care**

When necessary, licence permission and ethical approval was secured. The data collection started with establishment of the sample for this study (*Paper IV*). All hospital records for patients born between 1957 and 1976 at the GenP unit compiled a sample frame and those who were born the fifteenth day every month were selected in a systematic sample. The GenP hospital records were scrutinized and those who were born the fifteenth day every month were selected. A total of 205 patients were found. Twenty-two of them had been treated at the CAP unit at the hospital in Östersund and they were excluded. An additional seven patients had only a telephone contact with personnel at the GenP unit or had been referred to GenP from a doctor but had not appeared at the agreed appointment. These seven patients were also excluded and 176 patients remained. However, register data from the National Patient Register showed that nine of these 176 patients had been treated in CAP in other parts of Sweden, and they were therefore also excluded. Therefore the final Non-CAP-group included 167 GenP patients that did not have previous history of care in CAP.

Information about diagnosis and type of hospital care was noted from the hospital records. Their national registration numbers were linked to the National Patient Register from which a list of treatment occasions between 1969 and 1999 was obtained (*Paper IV*). There were four types of information in the register:

- Data on the patient.
- Data on the hospital.
- Administrative data.
- Medical data.

In this study the patient data are gender and age, data on the hospital and department (clinic), administrative data used are the year of admission, the year of discharge, the length of stay and whether admission was acute or planned, and medical data are the main diagnosis.

## 7.2 STATISTICAL METHODS

The findings based on prospective data are descriptive in nature. All data analysis was performed using the SPSS for Windows, release 12.0 (SPSS Inc.) software.

The *chi-square* and *t-tests* were employed to analyse differences between categorical and continuous variables, respectively, with a P-value of < 0.05 being considered statistically significant in both cases (*Paper I-IV*).

Differences between proportions were analysed utilizing a *two-by-two cross table* and *Student's t-test*. Although the t-test has earlier been debated as valid for making such comparisons, extensive studies have shown it to be applicable also in these respects, and, consequently, the Student's t-test has been widely and successfully used for analysis of proportional data [110].

*Binary logistic regression* determined the effect of a set of variables on probability of a dependent variable — plus effect of individual variables. Binary logistic regression is a regression application for a dichotomous, dependent variable and when the independents are of any type. The logistic regression model is a non-linear transformation of the linear regression (*Paper II*).

The *Cox proportional-hazards regression model* was used for survival analysis (*Paper I*). The regression model is broadly applicable and the most widely used method of survival analysis. It offers the possibility of a multivariate comparison of hazard rates. Survival time was defined as (1) the interval between birth year and death or end of follow-up and as (2) the interval between diagnosis and death or end of follow-up.

Observed and expected numbers of deceased (*Paper I*) were calculated using the *prospective method* described by Hartz et al. [111] and the *SMR* method. The difference between observed and expected numbers of deceased was tested using the z test variable, [112] which we also applied in the SMR method:

$$z = \frac{D - E}{\sqrt{E}}$$

where D denotes number of observed dead, E denotes expected number of dead, and z the test variable is asymptotic normally distributed (0.1). If the absolute value of z is larger than 1.96, then the hypothesis of equal mortality is rejected (the 5-percentage level). The limit for the 1-percentage level is 2.58, and for the 0.1-percentage level, 3.29. All-causes' SMR and sex-specific SMR were calculated for the entire country and for Jämtland County.

The *relative risk* or the *risk ratio (RR)* was presented with 95% CIs (*Paper I*). The risk ratio takes on values between zero ('0') and infinity. One ('1') is the neutral value and means that there is no difference between the groups compared, close to zero or infinity means a large difference between the two groups on the variable concerned. A risk ratio larger than one means that group one has a larger proportion than group two.

The *odds ratio (OR)* is a way of comparing whether the probability of a certain event is the same for two groups (*Paper II*). An odds ratio of 1 implies that the event is equally

likely in both groups. An odds ratio greater than one implies that the event is more likely in the first group. An odds ratio less than one imply that the event is less likely in the first group. The odds ratio was presented with 95% CIs.

The *rate ratio* (*Paper II*) is most suited to study events in a constant domain while the denominator-i.e. the population at risk- is very large. The rate ratio was presented with 95% CIs (Wald).

### 7.3 ETHICAL CONSIDERATIONS

Personal registers are an inalienable part of the research design for longitudinal studies as carried out in this thesis. A comprehensive regulation of research on humans is of national and international nature. To the extent that personal data are processed in the framework of a research project the Personal Data Act (1998:204) that replaced the outdated Swedish Data Act from 1973 (SFS 1973:289) is applicable. Some personal information is particularly sensitive nature. These are referred to in the Act as sensitive personal data. All health information is considered sensitive in the law, regardless of disease. Sensitive personal data may be processed for research purposes under the conditions set out in the Personal Data Act [113].

This data collection started long before the Act concerning the Ethical Review of Research Involving Humans (2003:460) came into force and in some cases before the Personal Data Act (1998:204). The Ethical Review of Research Involving Humans includes, for example, research on living persons, research on the deceased, research on biological material from humans and research that involves the handling of sensitive personal data. Accompanying the new law an authority “Centrala etikprövningsnämnden” (the Central Ethical Review Board) and six regional councils was established.

The register study would be implemented within the general register licence for health and medical service and the research ethical principles in force at each data collection were carefully followed. An initial application for ethical permission was sent 1995 and was approved by the ethical review committee of the Medical Faculty of Umeå University: Um document no. 95-051.

The research plan was later amended to include issues of crime and drug abuse and about which patients were seeking GenP care without prior CAP contact. Following a request of the ethics committee, I received notice that the original license (Um document no. 95-051) could continue to apply to the register study on the CAP and future psychiatric morbidity and mortality (*Paper I and Paper III*) but that new ethical applications must be submitted for the parts of the project on crime and abuse and the part of the study round GenP patients without previously CAP care.

Additional applications for these issues were therefore sent in for ethical review. In 1999, ethical review committees of the Medical Faculty of Umeå University and the Regional Research Committee at Karolinska Institutet approved the expanded study on crime (Um document no. 99-023 and KI document no. 99-209) (*Paper II*). In 2000, ethical review committees of the Medical Faculty of Umeå University approved the

expanded study on “Health care consumption for a population of patients in GenP care in the Jämtland County that not had a contact with CAP” (Um Dnr 00-341) (*Paper IV*).

Every register search has also been approved by the authority responsible for the register.

Because of the revised legislation the head jurist of BRÅ performed a special ethical scrutiny of the request for material from the register of persons convicted of offences (BRÅ Dnr I 9-231/98) (*Paper II*). He stated that information for research purposes may be handed over if it had been clear that the information could be revealed without the detriment of someone or if there were no harm done. This is in line with the Official Secrets Act (1980:100) and its ninth chapter, the fourth section.

A final ethical approval was received from the regional ethical council in Umeå applicable for the second data collection in 2006 (Dnr 06-107M).

The chief physician of the CAP unit and GenP unit both respectively approved the reading of medical records within the general register licence for health and medical service regularized in the Official Secrets Act (SkrL (1980:100)).

## **8 SUMMARY OF RESULTS**

### **8.1 PAPER I**

One of the two questions asked in this study was if Swedish CAP patients continued to experience a heightened risk for premature death — despite overall health improvement that has occurred in Sweden. Mortality and causes of death were examined among 1,400 former CAP-patients.

#### **8.1.1 Mortality; male/female ratio**

The findings showed that Swedish CAP patients are currently running an elevated risk of early death. Twenty-four males and 14 females died. The male/female ratio was 1.7:1. Twenty-eight of the patients (74% of the deceased) died before age 30. The all-causes SMR for the deceased was higher ( $P < 0.001$ ) than the SMR for the general population of Sweden and for Jämtland County. The risk of dying was almost twice as high for young males as for young females and 50% of all deaths occurred more than ten years after CAP treatment.

#### **8.1.2 Causes of death**

Six patients died of somatic illnesses while the others died of unnatural causes. Suicide was the single most common cause of death (50%). Other unnatural causes were drug overdose, other accidents and suicidal intention unclear. Seven patients - all males who had experienced childhood histories of aggressive outbursts, difficulties controlling impulses, and troublesome psychosocial situations' - died in traffic accidents.

#### **8.1.3 Suicide**

The other question asked was what kind of information could predict later suicide?

Nineteen patients (11 males and 8 females, male/female ratio 1.4:1.) committed suicide. When including an additional patient where a suicidal intention was unclear, this entails an approximate suicidal death rate of 14.3 per 1,000 persons in the cohort of former CAP patients. Males often used violent means to commit suicide while most of the female suicide victims died of intoxication.

Although suicide was the most common cause of death, only two of the 19, who later committed suicide, had been initially admitted for CAP clinical care because of attempted suicide. Eleven of these 19 individuals exhibited obvious psychosocial risk factors related to their home environments at their first admission to a CAP unit. Two variables — problems at school and behavioural disorder — were the factors in the initial contacts that were found to be the most important for predicting premature death and suicide, irrespective of which statistical method was used.

## **8.2 PAPER II**

The hypothesis tested in this study was that children and youth, who were identified by CAP units as having behavioural and school problems and dysfunctional families, were at high risk to become criminals. A group of 1,400 former CAP patients was examined.

### **8.2.1 Registered criminality; male/female ratio**

Every third CAP patient treated between 1975 and 1990 (every second male and every fifth female) had been entered into the Register of Persons Convicted of Offences, which is a significantly higher rate than the general population. The male/female ratio was 2.3:1. The findings were compared to published results for patients from PBU who were treated between 1953 and 1955 and followed over 20 years. The former male patients in the present study were entered into the register for criminality at double the rate compared to the group of patients from the 1950s; and for girls, this rate increased sevenfold. Repeated criminality was common, a total of 315 (59%) reoffended.

### **8.2.2 Risk factors**

It was shown admission to CAP for behavioural disorder was the single most substantial risk factor for conviction of offences. Patients who had relationship problems also showed an increased risk. Both a split family and problems at school independently entailed nearly doubled risk later being entered into the Register of Persons Convicted of Offences.

### **8.2.3 Most commonly registered crimes**

The 530 former CAP patients were entered into the Register of Persons Convicted of Offences for more than 2,000 incidents of committing crime, which included 81 types of crimes. Larceny, burglary, driving without a licence, motor vehicle theft, petty larceny, assault, drunk driving and narcotics were the most commonly registered crimes. The most serious crimes were robbery (10 cases), rape (6 cases), arson (3 cases), manslaughter (2 cases), and murder (1 case).

### **8.2.4 Violent crimes and drug related crimes**

Violent crimes constituted 10% of all crimes identified in this study. Sexual crimes constituted 1%. Crimes related to alcohol and drugs constituted 13% of all the identified crimes. Patients diagnosed with schizophrenia did not commit more crimes than patients with other diagnoses, but they more frequently committed violent crimes.

### **8.2.5 Juvenile criminality**

Thirty persons were convicted before their first admission to CAP care. Those who were under age 18 at their first conviction constituted 40% of all those convicted, and they were responsible for 59% of the identified crimes.

### **8.3 PAPER III**

The goal was to obtain answers to a number of questions concerning a group of former CAP patients diagnosed during child- or adulthood as suffering from schizophrenia, schizotypal disorder, delusional disorders and/or psychotic mood disorders.

#### **8.3.1 The incidences of schizophrenia and psychotic mood disorders; male/female ratio**

By the end of the follow-up period 62 former CAP patients (26 males and 36 females, male/female ratio 1:1.4), 4.4% of the entire index group, had received an ICD-10 diagnosis of “F20-29: Schizophrenia, schizotypal and delusional disorders” (48 patients) and/or “F30-39: Psychotic mood disorders” (14 patients). The overall estimated incidence of first-episode psychosis per 10,000 person-years in the index group was 15.4 (17.1 for females and 13.7 for males). For patients 15-29 years of age, this incidence was lower for males (11.6 versus 16.7) but higher for females (14.2 versus 8.1) than in a study conducted in Australia by Amminger and colleagues [114].

#### **8.3.2 Age upon initial diagnosis of psychosis**

The first question was *at what age was the diagnosis made?* The mean age at the time of the first onset of symptoms was 21.4 years (SD 6.4 years) and corresponding median age was 18 years. A majority of these (27 patients = 44%) were diagnosed between the age of 13 and 17 years, 17 patients (27%) between 18 and 25 years of age, 10 patients (16%) between the ages of 26 and 30 years, and the remaining 8 patients (13%) were older than 30 years of age when first diagnosed.

#### **8.3.3 The continuity in diagnoses between CAP and GenP care**

*Was this diagnosis later changed and, if so, in what manner?* Of the 531 former CAP patients later admitted to GenP care in adulthood, (38% of the total study population), 20% received a diagnosis within the same ICD-10 category during both CAP care and GenP care, with diagnosis of psychosis at a younger age exhibiting the largest degree of continuity. Thus, of the 27 individuals given such a diagnosis prior to the age of 18, only two were diagnosed differently as adults.

#### **8.3.4 Information on early signs of psychosis**

*Were early signs of the disorder detectable prior to or at the time of admission to CAP care?* Changes in behaviour, including social isolation, refusal to go to school, loneliness and odd behaviour in general were the initial signs or symptoms most frequently observed prior or upon admission to CAP-care. However, this was not the overall picture regarding the category of schizophrenia. Among the individuals diagnosed with schizophrenia or psychotic mood disorders, symptoms such as motor restlessness, obsessive rituals and poor sleep were equally common, being observed in 44% of the cases. Patients in both of these groups also frequently demonstrated anxiety and depression at the time of admission.

### **8.3.5 Which CAP patients were later diagnosed as psychotic in GenP?**

One-third (21 patients) of these individuals were given their initial diagnosis of psychosis during CAP care. Two of these 21 patients were not treated later for this disorder in GenP care whereas the remaining 19 individuals were diagnosed with the same type of disorder as adults. The other 41 patients were not diagnosed as psychotic until they were patients in GenP care. More than a third (15 patients) of them was given the diagnosis “F90-F98 Behavioural and emotional disorders with onset usually occurring in childhood and adolescence” during CAP care, eight individuals received the diagnosis “F40-F48 Neurotic, stress-related and somatoform disorders” and six patients were diagnosed with “Z00-Z99 Factors influencing health status and contact with health services.”

### **8.3.6 Differences between diagnoses of psychosis during CAP and diagnoses of psychosis first during GenP care**

Finally, a question was asked *how CAP patients that later were diagnosed as psychotic in GenP differ from those who had already received a diagnosis before the age of 18 years?* The patients given diagnose of psychoses at an age of 25 years or older exhibited unspecific psychopathological symptoms, but did not exhibit any signs of a possible psychotic disorder during their CAP care. In adolescence acute psychoses were more common.

## **8.4 PAPER IV**

This study examined the need for medical care in childhood and adolescence in a group of 167 GenP patients born on the fifteenth day each month between the years 1957 and 1976 treated at the Östersund hospital (the Non-CAP-group). They had no previous CAP care and they were compared to a control group consisting of 487 former CAP-patients treated at GenP at the Östersund hospital (the CAP-group).

### **8.4.1 Male/female ratio**

The male/female ratio in the Non-CAP group (167) was 1:1.4 and in the CAP group (487) 1:1.7.

### **8.4.2 Psychiatric inpatient care in adulthood**

A total of 49 patients (29%) in the Non-CAP-group had been inpatients at a GenP ward as adults compared to 53% in the CAP-group ( $P < 0.001$ ).

### **8.4.3 Psychiatric diagnoses in adulthood**

It was found that the CAP-group more often than the Non-CAP group had been treated in adulthood for Mental retardation (F70-F79), Intentional self harm (X60-X84), Unspecified mental disorder (F99), Disorders of adult personality and behaviour (F60-F69), Behavioural and emotional disorders with onset usually in childhood and adolescence (F90-F98) and contact with health services of other reasons (Z00-Z99). The Non-Cap group had more often than the Non-CAP group been treated in adulthood for “Injury, poisoning and certain other consequences of external causes” (S00-T98).

No differences were found between the groups regarding the frequency of other diagnoses.

#### **8.4.4 Hospital care in childhood and adolescence**

The Non-CAP-group had more often needed medical treatment compared to the general population.

#### **8.4.5 Paediatric care**

More than a third (36%) of the 151 treatment occasions in childhood and adolescence in the Non-CAP-group occurred in paediatric care and a third (32%) in different surgery clinics. In the CAP-group, 51% of the 1,226 treatment occasions in childhood and adolescence (the 492 treatment occasions in CAP excluded) occurred in paediatrics and 22% in surgery clinics. The CAP-group needed paediatric care more often than the Non-CAP-group ( $P < 0.001$ ). The ages when the patients had their first stay at a paediatric ward were similar between the two groups.

#### **8.4.6 Diagnoses in childhood and adolescence**

While the CAP-group more often had been treated for “skin problems” including skin infections and eczema (L00-L99) ( $P < 0.001$ ) and disorders involving the immune system (D50-D89) ( $P < 0.05$ ) the Non-CAP-group had more often been treated because of “Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified” (R00-R99) ( $P < 0.01$ ), and “Congenital malformations, deformations and chromosomal abnormalities” (Q00-Q99) ( $P < 0.05$ ). Psychiatric diagnoses, given during paediatric treatment were few in the Non-CAP-group and found on three occasions. They were more frequent (17%) in the CAP-group. Eleven patients in the CAP-group were treated in paediatrics for Anorexia Nervosa (F50.1) and another six for “Persistent somatoform pain disorder” (F45.4). On 12 occasions, and only for the CAP-group, psychiatric diagnoses were given after care in other somatic clinics besides paediatrics. In total, 47 patients (10%) of the 487 belonging to the CAP-group had been given a psychiatric diagnosis during care by other departments than CAP.

#### **8.4.7 Diagnoses that are possible predecessors to psychiatric diagnoses**

Two patients in the Non-CAP-group were treated each once for the condition of a specific diagnosis such as “Asthma.” In contrast, nine patients in the CAP-group were treated for such specific conditions on 94 occasions.

In the category of diagnoses: “S00-T98 Injury, poisoning and certain other consequences of external causes” it was found that one such diagnosis was given to a patient in the Non-CAP-group while 21 patients in the CAP-group had been given such diagnoses on 22 occasions.

Concussions, other head injuries and burn injuries were found in three patients in the Non-CAP-group and in 13 cases in the CAP-group.

Headaches and abdominal pains without a plausible somatic origin were found in 15 patients in the CAP-group on 18 occasions, but not at all in the Non-CAP-group.

More unspecific diagnoses such as an observation and evaluation for possible disorders, hospital care for social reasons and other psychosocial circumstances emerged only in the CAP group. Seventeen patients were treated on 18 occasions for such reasons. In the CAP-group only four cases of treatment for enuresis and only one case of treatment for encopresis was found.

#### **8.4.8 A retrospective analysis of the Non-CAP-group from GenP to paediatrics**

Retrospectively it was found that five of ten patients in the Non-CAP-group who were recorded to have had alcohol / drug abuse diagnosis in the category “F10-F19 Mental and behavioural disorders due to psychoactive substance use” had been hospitalized at least once in childhood and adolescence. One of them had been given a diagnosis that was linked to psychiatry when treated at a paediatric unit.

Eight patients were diagnosed in the group “F20-F29 Schizophrenia, schizotypal and delusional disorders.” Two of the patients had a history of somatic hospital treatment before they turned 18 years of age. None of the patients were found to have had a psychiatric linked diagnosis in childhood or adolescence and no one had been treated at a paediatric clinic.

In adulthood 32 patients were given a diagnosis in the group “F30-F39 Mood disorder.” Ten of these 32 patients had been in somatic hospital treatment before the age of 18 years. Three had been treated at a paediatric unit but no one had a diagnosis linked to psychiatry in childhood and adolescence.

Sixty patients were as adults given a diagnosis in the group “F40-F48 Neurotic, stress-related and somatoform disorders.” Twenty-eight of them had had been treated in somatic units as children or adolescents. One patient had been given a diagnosis that was linked to psychiatry. Eight had been treated in paediatric clinics.

Four patients with eating disorders and one patient having a sleep disorder in the Non-CAP-group had been given diagnoses within the category “F50-F59 Behavioural syndromes associated with psychological disturbances and physical factors.” One of them had a treatment occasion in childhood at a paediatric clinic and was then given the diagnoses “Other nutritional deficiency / investigation of the digestive system.”

Of the seven patients in the Non-CAP-group who were given diagnoses in the category of “F60-F69 Disorders of adult personality and behaviour,” five patients had a previous treatment occasion in childhood of whom three had been treated in paediatrics. One of them had a diagnosis linked to psychiatry.

## **9 DISCUSSION**

### **9.1 METHODOLOGICAL CONSIDERATIONS**

#### **9.1.1 Validity and reliability**

The quality of a study can be discussed with the terms validity and reliability. Both concepts can be divided into sub-concepts.

The concept of validity (including the sub-concepts criterion validity, face validity, predictive validity and communicative validity) has been considered in many ways in view of the measures used, the research setting, and the whole research design in order to secure the possibility to reproduce the study.

Referring to the reliability, the following can be said. The protocols and the data used in this study have not been changed during the long observation time. However, no measures on an inter-reliability rate (whether or not the ratings given by two raters are comparable) exist in regard to how the information from hospital files and registers were transformed into the protocols. This was done only by one person and depending on his pre-understanding (conformability) of the available information which may be both an advantage and a limitation.

#### **9.1.2 The design of the studies**

The designs of the studies, using both retrospective and prospective longitudinal approaches, were well suited for the goals of the studies and made questions possible to answer in a satisfactory way.

The index groups for papers I-III is the same total sample where eight individuals not covered by the national registries and twelve who subsequently emigrated during the follow-up period were excluded. In the Non-CAP-group described in paper IV ten per cent of the patients were born abroad. Their psychiatric histories did not contain any information on previous psychiatric care. However, the dates for their migration to Sweden are unknown and official information on any somatic/psychiatric treatment before their arrival to Sweden is lacking, which is a possible limitation of the study design to keep in mind.

Although the follow-up period is relatively long for the 1,400 former CAP patients, they are still relatively young. At the end of the follow-up period, the youngest was 26 years old while the oldest was 46. Most likely additional clinical information of value for psychiatrists and child and adolescent psychiatrists will emerge if they are followed over an extended time period. This is even more relevant for the Non-CAP-group (described in *Paper IV*) for which the follow-up period is shorter (four years).

### 9.1.3 Quality of the hospital data/psychiatric registers used

Some of the primary information was obtained from psychiatric hospital records, which in many aspects are not scientifically rigorous instruments of examination. However, the quality of these records was considered to be satisfactory for the study and they contained information provided by parents, school personnel and other authorities. They were all assessed by the same person using a protocol set up for the study. As mentioned above this could be an advantage supporting the validity and reliability of the study as “everyone was measured using the same measuring-stick” but may indicate limitations as well. This must be kept in mind when the results are interpreted.

Within psychiatry, there are two parallel diagnostic systems, the WHO ICD-system and the American DSM-system published by APA. They have both undergone repeated revisions. The current versions, ICD-10 and DSM-IV-TR, will soon be replaced by ICD-11 and DSM-V [115-118]. The revisions include increasingly more specific and detailed descriptions of diagnostic criteria, which allows for increased precision of diagnostic work and to compare the prevalence of disorders in different countries and continents. However, there is a significant overlap between several diagnoses, which have given a rising concern on comorbidity of disorders vs. overlapping of symptoms, as one individual can fulfil the criteria for a variety of psychiatric diagnoses at the same time [7]. The unreliability of psychiatric diagnoses has been and still is a major problem in psychiatry, especially at the clinician’s level [57].

In Sweden, the WHO ICD-system is the official way to register psychiatric diagnoses and disorders, but a decision was made by the Swedish Association for CAP in 1987 to use the DSM system and the ICD-10 concurrently in clinical practice.

ICD-10 and DSM-IV include multiple perspectives for assessing patients. The patient is assessed regarding symptoms, behaviour, personality traits, stress, ability to manage relationships, capacity to work and leisure time interests, etc. Mental and/or somatic comorbidity is assessed. A mental status usually consists of different aspects such as behaviour, motor symptoms, emotional symptoms, perceptual symptoms, cognitive symptoms and somatic symptoms [8, 119].

A view of multi-causality and of a multi-stage disease processes or the concept of the “Disease Causal Chain (DiCC)” makes it possible for psychiatry to identify different forms of expression related to mental illness, without the need to identify a definite reason why the disturbance occurs. Any complex disease process can involve some, or all of, at least seven of the following stages: preparation; initiation; promotion; retardation; progression, disease onset; and the strengthening / weakening of the severity and / or prevalence of the disease. Each of these stages could be triggered by co-causal factors [120].

Magnus Kihlbom, a well-known Swedish child psychiatrist, psychoanalyst and clinician, has discussed the challenges doctors meet with when making psychiatric diagnoses in GenP and CAP. He identifies several different types of diagnoses: 1. The aetiological explanatory diagnosis identifying a disease with a known cause and prognosis; 2. The syndrome diagnosis indicating a well-defined and typical condition where prognosis is known but the cause is unknown or only partially known; 3. The

diagnosis criteria are descriptions of symptoms or behaviours for which both cause and prognosis are largely unknown; 4. The category diagnosis indicate a qualitative change that defines the disease. You have a disease or not, you are either sick or healthy and the dimensional diagnosis indicates a risk, a quantitative change along a continuum or a normal curve. Kihlbom makes a further distinction between the descriptive diagnosis (observable) and the phenomenological diagnosis (understandable). Kihlbom states that a good child psychiatric diagnosis should be both descriptive (for example by using ICD or DSM) and phenomenological [121].

The ICD-system has been used for this study. A disadvantage is that the diagnoses in the hospital records and in the diagnostic registers were initially based on either ICD-8 or ICD-9 until 1997 when ICD-10 was introduced in Sweden – because of this all diagnoses have been re-categorized according to ICD-10 using translation instruments from official authorities [122, 123].

Causes for admission to CAP have been used in this study as independent variables (*Paper I-III*). In Jämtland, these causes had been defined at admission to CAP by a group of experienced professionals at the clinic in accordance with a list of causes structured by the Swedish Association for CAP. These data can be looked upon as having a clinical significance when assessing the later outcomes of the patients.

The CAARMS instrument (used in *Paper III*) is basically a manual for a personal interview. In this study it was used for the interpretation of information on psychotic symptoms extracted from the hospital files. No concurrent validation of the data was carried out using interviews. This lack of validation is a limitation when interpreting the results.

In the National Patient Register the quality of the information sent in to the Register varies from county to county. Data from some counties are of a high quality while the data from other counties are not so good [124]. That the National Patient Register only covers inpatient care is also a shortage.

Both the odds ratio and the risk ratio were used in the statistical calculations. Those ratios can be compared with each other. The risk ratio is easier to interpret than the odds ratio. However, in practice the odds ratio is used more often. This has to do with the fact that the odds ratio is more closely related to frequently used statistical techniques such as logistic regression [110]. Given a certain set of data, odds always differ upwards from risk. The relation between two risk figures may be expressed in various ways, one of which is the risk ratio. In the case of two odds figures, the choice is usually the odds ratio. With a certain set of data from two groups, the odds ratio is not identical to the risk ratio (except when both are equal to 1). The odds ratio always magnifies the inter group difference. Due to this one must take into account whether reported ratio figures denote risk ratios or odds ratios when assessing published data [125].

#### **9.1.4 Missing data**

In the study cohort containing 1,420 former CAP patients (*Paper I-III* and some of them in *Paper IV*) eight patients were not found in the National Registration. Two of them were refugees seeking permit and may have been expelled from Sweden. Three persons had earlier been living abroad or had a parent still living abroad and they may have moved from Sweden without registration of the emigration. For the remaining three no plausible explanation can be made.

Twelve patients had emigrated and were therefore excluded. Six of them moved to Norway, two to the USA and one respectively to Belgium, Israel, Italy and Germany.

There is also an attrition rate of 6-8 percent of “data loss” in the National Patient Register and there is great variation in the attrition rate between the different county councils. The “loss of data” from the Jämtland County (in 2006 5.8%) was similar to the Swedish mean value over time [126].

In the Non-CAP-group (described in *Paper IV*) ten per cent of the patients were born abroad. Their psychiatric histories did not contain any information on previous psychiatric care.

Periodically diagnoses in outpatient care have been missing from CAP since there was no obligation reporting diagnoses in outpatient care to The National Board of Health and Welfare. From 1987 the National Patient Register covers all public, inpatient care in Sweden. The Centre for Epidemiology (EpC) has data recorded from earlier years, 1964-1986, for somatic care and 1973-1986 for psychiatric care. Jämtland County Council was one of the first to report data to the register, beginning already in 1964. Sixty-five percent of the index group (*Paper I-III*) was born in Jämtland or in one of the other counties reporting from 1964 and onward. As the register does not cover the whole country for those early data about early inpatient care, data for some of the older patients in this study might be missing. An effort was made to obtain all places of domicile with the intention to look for hospital records for the study group from all places they had lived, but this was not feasible due to difficulties obtaining information from Local Tax Authorities [127].

#### **9.1.5 The possibility to generalize the results**

Although comparisons with an earlier longitudinal study of outpatients in Stockholm [17] and an unpublished comparison with CAP inpatients in the Stockholm area from the early 80s reveals very few significant differences, it should be kept in mind that the patients came from a sparsely populated area. Östersund, the only city in this county, was during the follow-up period a university town; a Swedish military centre; and an average, modern Swedish city still small while the rural areas of Jämtland differed significantly from the Stockholm area.

The differences are significant when it comes to how mental health services are utilized. People in Stockholm have more than twice as many treatment occasions as people in Jämtland [126].

The fact that Jämtland County had only one regional hospital with one CAP unit and one GenP unit for the whole population made it well suited for a study of this kind. The study population is simple to describe and it is homogenous. More than half of the former CAP patients that are described in all four papers lived in the county area at the end of the observation time, and sufficient data was obtained for 98.6% of the original cohort.

## **9.2 REFLECTIONS ON THE FINDINGS**

### **9.2.1 A summary of the main findings**

An initial question was what should happen to the CAP patients later in life. Looking at the overall outcome the situation is serious. An increased risk of premature death was found. Every second male and every fifth female was registered for criminality. Those who had an early onset of schizophrenia had an increased risk for developing severe chronic psychosis and required of long periods of hospital. However, it should also be noted that the continuity between diagnoses from childhood to adulthood was weak and that 40 percent of the cohort was not found in any register as adults.

Heterogeneity is a good word to use, when adult outcome in this group of CAP patients is described. There is a small group with clear psychiatric symptoms and disorders and a large group having different behaviour problems, social related problems and problems difficult to classify, and that disparity is problematic. It was long debated whether CAP was a medical discipline or not. The roots of CAP can be traced to pedagogic and found in discourses on education and deviant behaviour, in prevention of juvenile delinquency, in paediatric and in social work. In Sweden CAP was established as a medical discipline in the 1950s, but the discussion on the target group has continued. The CAP patient group is much more dispersed and difficult to classify than the more medically defined GenP patient group.

Some CAP patients groups are however worthy of special attention. The smaller group showing early onset of severe mental illness is a group that requires long term support and joint efforts between CAP and GenP. Patients having severe eating disorders constitute another important group who will need continued care from adolescence to adulthood. From my licentiate thesis, it can be stated that overarching knowledge concerning co-operation during transition from CAP to GenP is inadequate, in particular in how the transition can be arranged to be optimal for the patients and their families.

Another group in need of attention is those showing behaviour disorders in childhood and adolescence. Some patients in this group have the “poorest” outcome in adulthood. Two factors of the initial contacts with CAP, “problems at school” and “behavioural disorders”, were found to be the most important for predicting premature death and suicide. Admission to CAP for behavioural disorder constituted the most substantial single risk factor for later conviction of offences.

A behavioural disorder was independently a significant predictor for an overall “poor” outcome for both boys and girls. However identification of behavioural disorder was related to coming from a split family, being older than 13 years of age at first

admission, showing problems at school and need of inpatient care due to an insufficient social situation.

### **9.2.2 The overall outcome for the CAP patients**

A total of 835 CAP patients (59.6%) were found in one or more registers concerning GenP care in adulthood, mortality, conviction of offences or compulsory care of addicts. Three-quarters appeared in one register. Only 3% were found in three registers. More male patients than female had this “poor” outcome.

The CAP patients that were found on these registers, in comparison to the CAP patients not found on any of the registers, often had a split family, they had problems at school, they were older than 13 years of age at admission to CAP, more frequently they were inpatients at CAP, and behaviour disorder was a significant cause for admission to CAP resulting in a “poor” outcome. The relationship between behavioural disorder and “the poor” outcome persisted for male patients even after controlling for gender.

The available evidence suggests that a poor adult outcome is most likely the result of early onset of conduct problems associated with hyperactivity / attention deficits and poor peer relations. It is also evident that the poor outcome is a function of persistent and pervasive conduct disturbances in childhood rather than a consequence of transient or isolated antisocial problems [55].

The presence of eating disorders in early childhood or an eating disorder in adolescence confers a strong risk for an eating disorder in young adulthood [71] which was further substantiated in this study. Half of those with an eating disorder in childhood and adolescence were also admitted to GenP with the same problem.

### **9.2.3 The difficulties for the CAP patient group**

The first question asked about the CAP patient group was *whether the difficulties for the CAP patient group were a question of mental illness, disablement or behaviour disorders*.

In the current CAP patient population the gender distribution, as well as differences in symptoms and behaviour between the genders, appears to be similar to the patterns described in other CAP populations in Sweden as well as in the rest of the Nordic countries. It is also a heterogenic group like many other CAP populations [11, 16-18, 38, 45, 128].

Behavioural disorder was the most common cause for admission and the diagnoses block “F90-F98 Behavioural and emotional disorders with onset usually occurring in childhood and adolescence” was the second most frequent occurring diagnosis made at CAP. A clear gender difference was found, as three of four of the CAP patients diagnosed within the F90-F98 category block were males. Jonsson and Kälvesten [18] found in their study that boys who showed social behaviour disorders early in life had a very poor prognosis, in spite of a CAP treatment. In this study it was found that having been admitted to CAP for behaviour disorders predicted a negative overall outcome.

Anxiety was the most common single mental symptom found. 56% of the girls and 44% of the boys showed anxiety at admission to CAP. Together with stress related and somatoform disorders, eating disorder excluded, this was the second largest cause for admission.

Every third patient was found in the diagnosis block “Z00-Z99 Factors influencing health status and contact with health services.”

Seven percent of the patients had a diagnosis within the block “F70-F79 Mental retardation” or “F80-F89 Disorders of psychological development” and 2.2% of the patients were given a diagnosis within the blocks of psychoses.

*In summary* behavioural disorders, anxiety and stress related disorders were the most common reasons for admission to CAP. Psychotic disorders were rare. The Swedish Act on “Provisions for Certain Mentally Retarded Children” from 1954, with revisions 1967 and 1985, provides children in these groups with education and special support with no cost to families and this may explain why they make up such a small proportion of the CAP patients examined in the study.

#### **9.2.4 Did the former CAP patients become well functioning adults?**

Another question was *what happened to former CAP patients? Did they become well functioning adults?* These questions require a definition of the concept of a well functioning adult.

The definition used by the WHO is that health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The definition has not been amended since 1948 [129].

The broader concept of mental illness ranges from a serious mental illness to a reduced mental well-being expressed as a depressed mood or anxiety. Serious mental illnesses include various forms of psychoses, depressions and personality disorders. These conditions can be diagnosed within the classification systems for diseases and disorders. The group “other mental disorders - subjective self-perceived and self-reported complaints of mental nature which affect our general well-being” is more common [130]. Both groups share reduced mental well-being and often require psychiatric and mental services.

The question of whether the CAP patients became well functioning adults can from the present results only be answered in relation to the occurrence of mortality/suicides, later criminality, and later need of GenP care. To answer this question in a broader sense new personal interviews and new assessments of their overall life situation must be performed.

Forty percent of the former CAP patients were not found in any register during the follow-up. This means that they were still living, were not registered for criminality and had not needed further treatment/care provided by GenP.

Sixty percent of them had either died, were registered for criminality and/or needed treatment/care from GenP also as adults.

*In summary.* Using register data on their need of psychiatric care, the occurrence of criminality and mortality/suicides you can conclude that 60% of the former CAP patients had problems also as adults. This is an indication that they did not function well in adulthood which needs further discussion

### **9.2.5 Mental illness in adulthood**

A total of 531 persons or 38% had been patients at a GenP unit at end of follow-up. 487 were patients in Jämtland County (of whom 55 had been treated also in other Swedish counties) while 44 had not been hospitalized in Jämtland but had been inpatients in another county.

More girls than boys (male/female ratio 1:1.7) became patients in GenP in adulthood. Similar results have been found previous follow-ups of Swedish CAP patients [17] and from follows up other Swedish risk groups [22] findings. This may depend on gender typical psychiatric symptoms, i.e., with anxiety, depression and somatic symptoms more commonly expressed by girls, and acting-out behaviour more common in boys. The symptoms more commonly expressed by girls may be easier for professionals to manage and in turn may lead to making it easier for girls to receive help within CAP, and may entail that they may more easily seek help even within GenP. Acting-out behaviour on the other hand is often found disturbing by professionals, which is why the boys themselves may adopt a negative attitude towards CAP and to later GenP contact. Another explanation for these gender differences may be that the profession perceives girl typical symptoms as psychiatry while boy typical symptoms are perceived as anti social behaviour. Due to this they are more often referred to social welfare, dependence care and institutions for treatment of offenders instead. Findings from the register on criminality support the latter explanation.

In Jämtland County an average of 696/100,000 inhabitants was inpatients at GenP 1998-2001 [131]. The corresponding figure for the study group was 1062/100,000 ( $P < 0.001$ ). Valid information about occurrence of psychiatric care for the Swedish population in general is accessible for inpatient care. In the early 1990s [132] it was estimated that 2-3.5% of the population needed inpatient care during a specific year and the occurrence of psychiatric disorders was estimated to 9-19%.

The former CAP patient group constituted 11% ( $\pm 1$ ) of the patients within the same age having a hospital record at GenP, which indicates that the majority of patients in these age groups were not former CAP patients. Regarding the methodological aspects that have been discussed earlier the current findings can be interpreted differently.

If the prospective approach is used, the results show every third former CAP patient has become a future GenP patient. This can be seen from different angles. Some children and adolescents may show symptoms of early signs of adult disorders, why a later contact with GenP is a natural continuation of their needs. If this is the case, there may be a continuum from symptoms in childhood to symptoms in adulthood.

However, the results indicate that this is not the case for the majority of the former CAP patients as only weak connections were found between diagnoses given to patients in CAP and later to the same patients in GenP. According to ICD-10 diagnoses every fifth patient received a diagnosis within the same blocks at CAP as well as in GenP care. This was most obvious in the group of patients having mental retardation, other handicaps and early signs of psychotic disorders.

A plausible way to explain the weak connections between certain CAP diagnoses and later GenP diagnoses may be related to children's maturity and development. Children having age specific diagnoses or show crisis reactions and/or adjustment problems may show very unspecific symptoms due to the variance of normal maturation and development, which in turn may predict many different outcomes in adulthood.

Some symptoms of anxiety and behavioural disorders in childhood are reactions to environmental demands and/or reactions to psychopathological behaviour in parents. If this is the case, one can expect that the child will be referred for different reasons to CAP in childhood and seek help from GenP in adulthood. In this study children with such problems (for example children in conflict with parents, or children suffering from the conflicts between parents) often had CAP diagnoses within the ICD-group "Z00-Z99 Factors influencing health status and contact with health services" which in adulthood were followed by more serious psychiatric diagnoses, including substance abuse. Substance related disorders were almost four times as common within GenP as in CAP. For obvious reasons, an established abuse can be assumed to be more common in adulthood than in adolescence, but as the symptoms described above were found to precede later addiction diagnoses they should be taken seriously at CAP. These children together with children and adolescents who act-out, children with behavioural disturbances and abused children should be observed in particular by CAP in cooperation with authorities as school health and social welfare based on mutual professional knowledge.

The observations indicate that disorderly behaviour and attention deficit disorders in childhood could be anxiety-related symptoms and that anxiety in childhood may be associated with mood disorders. The findings indicate a relationship between behaviour disturbances and later depressive disorder diagnoses. This suggests that behaviour disturbance and attention deficit disorder in childhood can be an expression for depressive internal feelings.

*In summary* every third former CAP patient has become a future GenP patient. The former CAP patient group constituted 11% ( $\pm 1$ ) of the patients within the same age group having a hospital record at GenP, which indicates that the majority of patients in these age groups have not been former CAP patients. The connections between certain CAP diagnoses and later GenP diagnoses were weak. As will be discussed later, the results show that behavioural disorders per se have more impact on mortality and criminal development later in life rather than on GenP care in adulthood but nevertheless, behavioural disorders is also an important factor in childhood behind later psychiatric diagnoses.

## 9.2.6 The occurrence and nature of early signs of schizophrenia and psychotic mood disorders

Sixty-two former CAP patients (36 females and 26 males), 4.4% of the entire index group, had received an ICD-10 diagnosis either in the Schizophrenia group or in the group of Psychotic mood disorders. Forty-eight individuals had “F20-29: Schizophrenia, schizotypal and delusional disorders” and 14 individuals had “F30-39: Psychotic mood disorders”. In relation to criminality the schizophrenic group often committed violent crimes. The overall estimated incidence of first-episode psychosis per 10,000 person-years was 17.1. For patients 15-29 years of age, this incidence was lower for males (11.6 versus 16.7) but higher for females (14.2 versus 8.1) compared to an Australian study [114].

The following questions were analyzed:

*At what age was the diagnosis of psychosis made?*

The mean age of these patients was 21.4 (range 13–41 years), with 27 patients (44%) aged 13 – 17 years, 17 patients (27%) 18-25 years and 18 patients (29%) were older than 25 years of age. Females demonstrated an early onset more often than the males.

*Was this diagnosis later changed and, if so, in what manner?*

Only two of the individuals diagnosed as psychotic before the age of 18 years while under CAP care did not receive a diagnosis in the category of schizophrenia or psychotic mood disorders as adults. One of them was later diagnosed with an unspecified anxiety disorder and the other, who was treated for an acute episodic psychosis during adolescence, received a diagnosis in the area of autism. In 13 cases the CAP diagnoses were later altered during GenP care to other diagnoses within the same categories: 12 were placed in the same sub-category of “F20-29: Schizophrenia, schizotypal and delusional disorders” and one in the same sub-category of “F30-39: Psychotic mood disorders” at both time-points. Three patients with a CAP diagnosis in the sub-category of “F20-29: Schizophrenia, schizotypal and delusional disorders” were later categorized as “F30-39: Psychotic mood disorders” in adulthood. In contrast, three individuals treated during adolescence for “F30-39: Psychotic mood disorders” were later categorized in the sub-category of “F20-29: Schizophrenia, schizotypal and delusional disorders.”

In their 42-year follow-up of 38 patients with childhood-onset schizophrenia and 38 patients with other diagnoses Remschmidt and co-workers [133] also described re-diagnosing of former CAP patients as adults. Although their findings indicate diagnostic stability over time in the case of 91% of their patients, 11% with a CAP diagnosis of childhood-onset schizophrenia were given another diagnosis as adults.

*Which early signs of disorder were noted prior or upon admission to CAP care?*

Changes in behaviour, including social isolation, refusal to go to school, loneliness and odd behaviour in general were the initial signs / symptoms most frequently observed prior or upon admission to CAP-care. However, this was only the case with regard to the diagnosis of schizophrenia. Among the individuals diagnosed with schizophrenia or psychotic mood disorders, symptoms such as motor restlessness, obsessive rituals and

poor sleep were equally common, being observed in 44% of the cases. Patients in both of these groups frequently demonstrated anxiety and depression at the time of admission.

*Which patients received their diagnosis later in connection with GenP care and how did this group differ from those diagnosed earlier during CAP care?*

The patients given a diagnosis of psychoses at an age of 25 years or older had during their CAP care exhibited unspecific psychopathological symptoms, but no signs of a possible psychotic disorder. However, the shorter the period that elapsed from the completion of CAP care until admission to GenP care, the more frequently symptoms of a possible psychotic disorder were observed at the CAP unit, although these were not specific enough for a diagnosis to be established.

None of these patients were diagnosed with childhood-onset schizophrenia, which by definition, debuts before the age of 13 years [134]. As described by Rapoport and Remschmidt and their colleagues [79, 135-138], this rare disorders is most probably due to progressive brain degeneration and, it therefore is not surprising that none of the 1,400 CAP patients were afflicted.

The scientific literature contains few reports of investigations outside Scandinavia similar to the present one. In the Nordic countries, findings similar to my own have been reported by Dahl [139] who conducted a 20-year follow-up study of “a child psychiatric clientele with special regard to the diagnosis of psychosis”; by Pedersen and Aarkrog [140, 141] who performed a 10- and 20-year follow-up study of child psychiatric patients, and by Strömngren [142] in 1940 when he discussed “Episodic Psychosis in Adolescence.” Furthermore, Tyano and co-workers [143] made similar observations concerning “Transient adolescent psychosis” upon monitoring the stability of diagnosis in a cohort of Israeli CAP patients. As discussed above, the current results can be compared to those from a similar 20-year follow-up of CAP patients from the 1950s to the 1970s.

*In summary.* The findings indicate that disorders within the Schizophrenia group and in the group of Psychotic Mood disorders are not so common in CAP practice. In this cohort the mean age of the patients was 21.4 years when the diagnosis was set. Those with an early onset, before 18 years, were identified during CAP care. The larger group with a late onset usually exhibited unspecific psychopathological symptoms, but no signs of a possible psychotic disorder during their CAP care.

### **9.2.7 Mortality and suicide**

The findings showed that the CAP patients have faced an elevated risk of early death, despite overall improvement in health that has occurred in Sweden in recent decades. An approximate suicidal death rate of 14.3 per 1,000 persons was found. The risk of dying was almost twice as high for young males as for young females. The results are in line with international studies [144, 145].

Nineteen (50%) of the 38 former patients who died committed suicide. Although suicide was the most common cause of death, only two of the 19, who later committed

suicide, had been initially admitted for CAP clinical care because of attempted suicide. Eleven patients committed suicide within one year of their latest psychiatric treatment (CAP or GenP). Only two of these had been under treatment for schizophrenia (1 patient) and mood disorder (1 patient). Behavioural problems, problems at school, and crime were common, irrespective of the cause of death, whereas suicide attempts constituted a poor predictor for later suicides.

The findings of this study are in line with results from previous studies of Swedish CAP patients. In Alice Hellström's longitudinal study of behaviourally disturbed children [16] ten per cent of the cohort of 242 children (16 young males and 8 young females) died during the follow-up period. Of the 2,164 former PBU patients in Stockholm, an overall mortality rate of 2.1% (2.6% for males, 1.3% for females) was found. One-third of the deaths were suicides, and one-third of the deaths were caused by accidents or alcohol related illnesses [17]. Among the 222 average schoolboys followed for 20 years, 8 boys (3.6%), died during the 18-year follow-up (6 died of diseases and 2 from accidents) and in the delinquent group, 9% died in accidents or suicides (of whom 44% died before age 17) [18]. In a 30-year follow-up study of the former PBU patients, de Chateau reported a 4.8% mortality rate and a 1.5% suicide mortality rate. The death rate was twice as high as the expected death rate in a reference group of Stockholm males and females of the same age distribution [146]. In 1984, Rydelius [147] surveyed 1,206 CAP patients who underwent treatment between 1970 and 1980 in a Stockholm hospital. Two percent had died by the end of 1981. Similar results were found in Norway [47], Denmark [38, 148, 149], and Finland [150].

These results from Swedish prospective studies suggest a possible link between psychosocial background factors and early death due to accident and suicide [147]. A hypothesis regarding such a link was supported when tested in a 19-year follow-up study of 1,064 Swedish juvenile delinquents. Thirteen per cent of the delinquent young males and 10% of the young females had died, mainly from suicide and accidents [151]. The present findings are also in line with results from a recent Swedish study on predictors of suicide from the Swedish Pregnancy and Birth registers, which indicated that psychosocial factors (low maternal education, teenage motherhood) and factors relating to the pregnancies (multiparity, restricted fetal growth) were associated with suicide completion and suicide attempts among offspring [152].

Suicide attempts are common among Swedish CAP emergency patients in metropolitan areas [15]. In 1973, nearly every fourth emergency patient in Stockholm (32% of the young females and 7% of the young males) was referred for treatment for attempted suicide. In 1995, 16% of all CAP emergency cases in Stockholm were admitted because of attempted suicide (21% of the young females and 7% of the young males). Despite the high rate of attempted suicides in Swedish CAP clinical practice, Otto [153] found a low risk of successfully completed suicides in the emergency patient group in his 15-year follow-up study.

*In summary.* Suicide attempts are common among Swedish CAP emergency patients. In the Jämtland cohort 5% of the patients (71 individuals) were admitted for such attempts. The follow up showed in line with previous Swedish studies that a suicide attempt per se is not a strong predictor for a later suicide. The current results indicate

that delinquent children and adolescents have the highest risk of death, including suicide. This was found earlier in different Swedish prospective follow-up studies of CAP patients, children from the general population, and delinquent children and adolescents into the 1990s.

### **9.2.8 Criminality and a comparison with an earlier Stockholm study and other studies with focus on criminality development**

Fifty-four percent of the boys and 21 percent of the girls in the Jämtland cohort of CAP-patients were found in the Register of Persons Convicted of Offences at the end of the follow-up. The findings are in line with Scandinavian studies outside Sweden. In Norway, Kjelsberg followed 1,276 former CAP inpatients, 15-33 years, after hospitalization in childhood and adolescence; 1,095 could be traced [45, 46]. After excluding those who were entered criminal registers at the time of their hospitalization, 932 persons remained - of which 44% appeared in criminal databases. There were no significant difference between the Jämtland and Norwegian group.

Concerning boys, the findings are also in line with earlier Swedish longitudinal studies (see Table 1). These studies focused on boys as criminality among girls was rare in Sweden until recently. Nylander [17] published a 20-year prospective follow-up study of 2,164 patients (1417 males and 747 females) from the PBU clinics. After treatment they had been discharged in 1953, 1954, and 1955 then followed until the mid 1970s. To compare the Jämtland cohort to the Stockholm cohort, a sub-sample of the Jämtland cohort with a full 20-year follow-up period, 608 cases (325 males and 283 females) was selected (Table 7).

**Table 7. A comparison between 2,164 Stockholm PBU patients in the 1950s and 608 CAP patients in Jämtland that were followed 20 years**

	Stockholm		Jämtland		P-value
	Number	Percent	Number	Percent	
Primary material	2364		1420		
Emigrated	100	4.2	12	0.8	< 0.001
Deceased during follow up	50	2.1	38	2.7	0.281
Unusable data	50	2.1	8	0.6	< 0.001
Inpatient care at CAP	0	0	270	19	< 0.001
Less than 20 year follow up	0	0	484	34.1	< 0.001
20 year observation time	2164	91.5	608	42.8	0.004
Males	1417	65.5	325	53.5	< 0.001
Females	747	34.5	283	46.5	< 0.001
Age at end of follow up period					
20-31.5 years	1415	65.4	236	38.8	< 0.001
31.6 years or above	749	34.6	372	61.2	< 0.001
Registered for offences	344	15.9	228	37.5	< 0.001
Males	319	22.5	174	53.5	< 0.001
Females	25	3.3	54	19.1	< 0.001
Males/Females	12.8:1		3.2:1		< 0.001
Mean age at registration					
Males	20.6		19.8		< 0.001
Females	23.0		21.3		0.009
Number of convictions	988		863		
Males	947		681		
Females	41		182		
Males/Females	23.1:1		3.7:1		< 0.001
Convictions per person	2.9		3.8		0.401
Males	3.0		3.9		0.297
Females	1.6		3.4		0.986
Serious violent crimes	15	1.5	11	1.3	0.655

While the boy / girl ratio was 1.9:1 in the Stockholm cohort from the 1950s, more girls were CAP patients in the Jämtland cohort - with a 1:1.1 boy / girl ratio.

Compared to 22.5% of the Stockholm boys, 53.5% of the Jämtland boys were found to have been convicted of a crime during the 20 year follow-up after discharge from CAP care ( $P < 0.001$ ). Ninety-two percent of the convictions among the Stockholm boys and 91% in the Jämtland cohort occurred between the ages of 15-26. Among the girls, the corresponding figures were 3.3% compared to 19.1% ( $P < 0.001$ ). The Jämtland girls were younger than the Stockholm girls at the time of first conviction ( $P < 0.001$ ); while no age difference was found among boys.

The CAP organization in Jämtland was in the 1970s newly started and working according to the current opinions of the time period. Few relations were established to

other authorities while the Stockholm organization for PBU outpatient care was established in 1933 and worked hand in hand both with the Stockholm Child Social Welfare Board and “School Psychiatry”. The fact that the CAP unit was established in the Stockholm Public Schools in 1919 may well explain why the proportion of pre-school children was higher in the Stockholm cohort in the 1950s and why the Jämtland cohort was older at the end of a 20-year follow up (Table 7). This close cooperation between CAP, school psychiatry and social service may also be one of the explanations why later criminality was lower in the Stockholm cohort.

Until 1977, there was a special National Alcohol Register on alcohol related criminality including public drunkenness. Using this register, as shown in Table 1, it was possible to describe the relationships between criminality and alcohol abuse in previous prospective cohort studies of CAP patients, average children and youth and risk groups. It is a disadvantage that such an analysis could not be run for the Jämtland cohort of today. However, as the previous Jämtland CAP patients registered for criminality needed GenP care as adults due to diagnoses of substance related disorders and personality disorders, it seems relevant to assume that the rise in the consumption of alcohol in the Swedish population is one of the factors explaining the current findings of higher criminality found in both boys and girls from the Jämtland cohort compared to the Stockholm cohort from the 1950s. The relevance of this assumption, and the effect on criminality of the changes in the Swedish consumption of alcohol from 1916-1977 when Sweden had special Temperance Laws and until today, is supported by the results from Otterström in 1946 [154] and the results from Rydelius [22] and Rydelius & Nylander [155].

In three previous studies [22, 154, 155] similar results were found for girls who showed a low risk for later criminality. More girls were found to be registered for criminality in the present study compared to the CAP patients from the 1950s, which suggests effects of a secular trend over the past 30 years. This secular trend with an increasing number of girl patients later registered for criminality is in line with Kjelsberg’s recent findings in Norway [156].

*In summary.* The high risk for the former CAP patients, both boys and girls to end up with criminal records in adulthood is alarming. This is a true challenge for clinical practice and research in CAP. The change from strong supportive and protective systems for Swedish children that has taken place from 1970 until today, further discussed below, together with the rise of the average alcohol consumption in Sweden may be factors explaining this serious situation.

### **9.2.9 The gender perspective and sex differences**

The aims of this study have not included the gender perspective and sex differences per se. This will be the focus for future analyses of the study groups. The group of CAP patients in this cohort is similar to previous descriptions of Swedish CAP patients in the following aspects: The typical male Swedish CAP patient is still “a 10-year-old troublesome boy” and the typical female patient is still “a 14-year-old depressed girl.” Both boys and girls come from families with psychosocial difficulties and have shown problems at school. However, and in contrast to the results from previous Swedish

studies, girls in this cohort are showing a high risk for delinquency and registrations for criminality in adulthood. This is a matter of serious concern and in need of further exploration.

### **9.2.10 A comparison of GenP patients with and without a history as recipients of CAP care.**

The aim was to answer the following questions: Who were the patients in need of GenP care without a previous contact with CAP? Did the frequency or the seriousness of their need of GenP care differ from the former CAP group? What were the needs for hospital care during childhood and youth for this group and the former CAP-patients?

*Who were the patients in need of psychiatric care without a previous contact with CAP?*

Ten percent of the patients in the Non-CAP-group were born abroad. Despite this, the Non-CAP-group was in many respects similar to the CAP group. Few differences were found in the gender distribution or the diagnoses in adulthood.

*Did the frequency or the seriousness of their need of psychiatric care differ from the former CAP group?*

Many similarities between the Non-CAP-group and the CAP-group were found regarding the nature of psychiatric illness in adulthood. However, a highly significant difference appears in relation to inpatient care. A third of the Non-CAP-group had been inpatients at GenP which was a significantly smaller proportion compared to the CAP-group. With the assumption, supported by the files and psychiatric histories, that inpatient care is given to patients with more complex and severe psychiatric symptoms, problems and needs; it appears the former CAP patients have more GenP needs also as adults. In the CAP-group, an early diagnosis within the category of “Schizophrenia” was the variable found to be most related to need of psychiatric care from childhood and adolescence into adulthood [157].

The presence of eating problems in early childhood or an eating disorder in adolescence indicates a strong risk for an eating disorder also in young adulthood [71]. None of the five Non-CAP-patients who were treated for an eating disorder in adulthood had received treatment for a similar condition in childhood and adolescence.

Childhood disruptive behaviour has powerful long-term effects on adult antisocial outcomes, which continue into middle adulthood [87]. Those who were in adulthood diagnosed with “F60-F69 Disorders of adult personality and behaviour” had received treatment in childhood, but for other reasons than symptoms related to the diagnosis. The need of treatment in childhood reflected more parental neglect and possible attachment problems; only one patient presented in childhood with more typical signs of a problem linked to psychiatry. Diagnoses within the category J00-J99, i.e. respiratory disorders, were found among nearly every third patient in the CAP-group and among every fifth patient in the Non-CAP group. Studies of asthma in preadolescent children has shown that such problems are often associated with emotional and behavioural problems [158] and/or to panic attacks [159]. That the CAP-groups needed treatment for problems in the category J00-J99 may reflect

parental problems to handle a minor medical issues rather than a severe psychiatric disorder in the child itself.

*What were the needs for hospital care during childhood and youth for this group and the former CAP-patients?*

The findings show that the Non-CAP-group more often needed non-psychiatric hospital care in childhood and adolescence compared to the general population. However, differences were not found between the Non-CAP-group and the general population in reference to diagnoses covering mental and behavioural disorders. Instead, the Non-CAP-group more often had diagnoses within the categories of “S00-T98 injury and poisoning of external causes”. Hospital care due to such causes may be signs of later psychiatric illness worth to note. The CAP-group needed more and repeated non-psychiatric hospital care because of unspecific reasons compared to the Non-CAP-group. Extensive and repeated hospital care of children and youth when no typical somatic disorder is found may be a sign of later psychiatric illness in itself. Despite the long Swedish history of consultation / liaison linking CAP and paediatrics to each other [160] the results indicate a need to further develop these services.

*In summary*, the larger group of GenP patients without a history of previous treatment in CAP was in many respects similar to the former CAP patients. However, the former CAP patients had more often need of inpatient care as children. The increased need for paediatric and other somatic care for symptoms may reflect parental neglect, possible attachment problems and parental incapacity to handle minor health problems rather than a severe psychiatric disorder in the individual child.

### **9.2.11 The three different types of patient groups that come for GenP care as an adult.**

The analysis and the findings of this study and the results from the follow up of the other CAP-patients indicate at least three different types of patient groups that come for GenP care as an adult.

One group of patients seem to follow a possible “developmental trajectory” beginning with response symptoms to parental neglect, and successively showing need of unspecific somatic hospital treatment during childhood, school failure, later referral to CAP because of behavioural problems and finally need of GenP care often related to a high risk for suicides, issues related to criminality such as alcohol/drug abuse (F10-19), neurotic and stress-related disorders (F40-48) and personality disturbances (F60-F69). This trajectory is discernible from data available in health services if interpreted in a correct way.

Another type of patient group displays problems first in adulthood in the category (F40-F48), i.e., neurotic and stress-related disorders, in which few, if any, typical symptoms or behaviour have been detected that the health services could otherwise identify in childhood. These problems may develop from accumulated stressful life-events.

The third type of patient group concerns the development of Schizophrenia (F20-F29) and Mood Disorders (F30-F39). The results from the follow-up of the former CAP-

patients and the previous 20 year follow-up of 2,164 CAP-outpatients from the Stockholm Child Guidance Clinics from the 1950s to the 1970s indicate that only a small fraction of patients with Schizophrenia and Mood Disorders show typical symptoms during childhood and early adolescence. The majority seems to develop their typical symptoms as adults. Further, the patients in this group type, who had previously been CAP-patients before symptoms of schizophrenia and Mood Disorders emerge, have been found to only show unspecific symptoms during CAP care.

### **9.2.12 An overview of changes of supportive systems for children in Sweden**

In Sweden, strong supportive systems for children were established between 1920 and 1970. A child social-welfare law was passed in 1924, which mandates each municipality to create a planning board for children's social well-being, including efforts from society to focus on a more strict social regulation to prevent delinquency. The school system was investigated as a means of delivering services. From 1940 to 1970, a differentiated public school system (based on curative education) was established. Two parliamentary decisions (1946 and 1958) stipulated CAP care as a free service to all children, youth, and their families. In- and outpatient clinics and treatment homes were required to be founded and organized in every county council. Since the 1920s, when CAP care was first established, school psychiatry was developed to support mentally retarded and learning disabled children. An important objective when passing the child social-welfare law and providing free CAP services was to prevent and reduce juvenile delinquency.

Up until the 1970s treatment and support given to children, youth, and parents were based on close co-operation among CAP units, mental health staff at schools, and child social-welfare boards in the municipalities. Multidisciplinary treatment strategies included combinations of medical methods; individual psychological treatment of children; educational methods; "change" at schools; parental treatment; and environmental change (treatment home, foster home, and adoption).

From the 1970s until today, a great change has occurred in what started as fully available support systems for children. Starting in 1969, the public school system, based on principles of curative education, was reorganized. Teaching strategies based on the individual's cognitive capacity in small groups was replaced by an "inclusive" school in which special education and small groups were looked upon as "excluding" factors and thus abandoned. Mental health staffs in the public schools were downsized. In many places, positions were eliminated, such as school psychiatrists, social workers, and school psychologists, so that only a few school nurses remained. From 1982, the child social-welfare law changed. The system with specialized child welfare boards in each municipality was abandoned in favour of generalized boards that deal with overall social services for inhabitants. Generalists replaced child social-welfare workers who were especially trained to work with children and youth. In many sites in Sweden, treatment strategies, based on theories from psychodynamics and family theories, replaced child psychiatric multidisciplinary approaches that were used until the 1970s. Consequently, close co-operation among CAP units, school psychiatry, and child social-welfare units declined.

### **9.2.13 Possible mechanisms to understand future delinquency**

Patients admitted to CAP care are a more vulnerable group compared to average children and youth why their risk for future criminality might be increased. In their study of 111 young Swedish male criminals (examined by a forensic psychiatrist), Adler et al. [161] found a common multi factorial background involving constitutional vulnerability together with social problems and school failures. The most important risk factors associated with juvenile criminality were malfunctioning parental care and supervision, school problems, suspension from school, influence from criminal peers, unstable family situation, unemployment, and heavy alcohol and narcotics use.

According to Hirschi theory [162] about social bonds, the relevant question is not what makes certain individuals commit crimes but rather what prevents us all from committing crimes. The answer rests with social regulation, which is applied through integration into social institutions i.e., into the family, school systems, health care systems and the surrounding society. Malfunctioning parental care and supervision, behaviour disorders and school problems were obvious risk factors in this study. Split family was one of the variables that had an effect on criminal development. In a split family, there is an increased risk for deviant behaviour and criminality among the children [163]. A basic theory about the connection between a split family and criminal behaviour of children is what Loeber and Stouthamer-Loeber calls the “splitting paradigm” theory [164]. Split family may in turn be the result from parental malfunctioning leading to failure of social control within families. Rutter [165] states that it is crucial to differentiate between risk indicators and risk mechanisms. For example, a family split-up does not necessarily put the child at risk, but the process that arises from the split-up creates risk mechanisms such as problems associated with being a single-parent or parent conflicts in which the child might be involved and where social control is lacking.

*In summary*, the changes in the organization of Swedish child social welfare work and Swedish school system and in the treatment strategies used in Sweden’s CAP care may together with the diminishing co-operation between CAP, school psychiatry, educators and child social welfare agencies has since the early 1970s until today put children who are already at risk in a worse situation than compared to the situation 40 years ago. Their need of social support and social regulation seems to have been forgotten. Of special concern for CAP and GenP in this respect is that the schizophrenic patients in this study more frequently committed violent crimes.

## 10 CONCLUSIONS

*As a summary the following can be said:*

The typical male Swedish CAP patient is “a 10-year-old troublesome boy,” while the typical female patient is “a 14-year-old depressed girl.” Both come from families with psychosocial difficulties; have problems at school and risk later delinquency and/or alcohol and/or drug abuse.

Children admitted to CAP before the age of 13 usually show behavioural symptoms and adjustment difficulties in peer groups and in school. Children’s symptoms and behaviour problems often co-occur with psychosocial health problems among other family members. Youth admitted to CAP have more often than when younger in school and preschool developed their “own problem” where the existence of parallel health problems among other family members are not so pronounced.

At least every third CAP patient, girls more often than boys, will later seek help in GenP. Nonetheless, only a few patients in the CAP group were admitted to CAP due to symptoms foreboding mental illness.

The greatest risk to CAP patients face in adulthood is the development of addiction and crime.

Psychotic disorders have been and continue to be relatively uncommon among patients admitted to CAP care in Sweden.

The present empirical findings indicate that psychotic disorders in average have a debut during late adolescence and early adult-life with a mean age of 21.4 years when the diagnosis is set. Disorders in the ICD category “F20-F29: Schizophrenia, schizotypal and delusional disorders” are more common than those classified as “F30-39: Psychotic mood disorders.” Psychotic mood disorders are rare among children and adolescents.

In the case of mortality and suicide it may be discerned from the findings in this thesis that although death rates among Swedish children and adolescents in general have decreased over the past 100 years, the elevated death rates in CAP cohorts have not changed. Furthermore, it seems as if death due to natural causes in this group is less prevalent today while the risk of suicide and accidental death has increased. Notwithstanding, suicide attempts seem to be a poor predictor for future suicide in these age groups. The findings suggest that in CAP practice, variables such as childhood psychosocial risk factors and social maladjustment may be the most important predictors of early death, including suicide.

There is a group of patients treated in paediatrics and in CAP during childhood and adolescence before becoming later patients in GenP when they are adults. They could most likely be identified more efficiently during childhood if closer collaboration is developed between paediatrics and CAP services. They constitute however only a small percentage of the patients in the same age-groups in need of GenP care as adults. This

larger group of GenP patients has had a larger need of somatic hospital inpatient-care before the age of 18 years when compared to the general population but less than the group described above. Most probably they cannot be identified in the same way. Hypothetically, their need of GenP care as adults may develop from accumulated stressful life-events.

Regarding criminality the current findings may increase the understanding of the risk for criminal development in CAP clinical patients. It is unlikely that CAP care causes criminality, but it has not prevented it. Over the past 50 years, the percentage of Swedish boys admitted to CAP care and later registered as criminals seems to have doubled. The percentage of girls has increased almost seven times. While individual and family factors seem to be very much the same, comparing results from CAP patients from the 1950s to the current cohort, this higher risk of later criminality is hypothetically the result of rising alcohol consumption in Sweden, comorbid use of illegal drugs, and changes in the organization of child social welfare work, the school system, and CAP methods and practices that has occurred since 1970. In turn this may have put children who are at risk in a situation where their need of social support and social regulation has been neglected.

The present study is a step in the process to better live up to the intentions of the Community Mental Health Care reform and as well to the official reports on children and adult mental health demanding improved co-operation between the psychiatric branches of learning and between psychiatric clinicians and other authorities influencing mental well being in the Swedish society. These improvements in health care organization and always keeping the patients best interests in mind can help improve the prognosis for children who are at risk.

# **11 CLINICAL IMPLICATIONS AND FUTURE RESEARCH**

## **11.1 CLINICAL IMPLICATIONS**

There is a large group of CAP patients that develops serious social adapting difficulties already in childhood. This point to the need of improved co-operation and exchange of knowledge with social services, school health service and units for treatment of offenders. In turn, this seems to be particularly important for the group of youth who have been found already in their teen age years to commit suicide or die from sudden and violent causes. This is also important for children and youths with aggressive behaviour to lessen the risk to develop addiction and criminality.

It seems reasonable to conclude that problems in school, behavioural symptoms, and conduct symptoms are more important in the calculation of risk of early death or suicide than are suicidal attempts. The results bring into focus the question of how prevention of suicide in children and adolescents should be managed. Today, few evidence-based suicide prevention methods or programs have passed the scrutiny of meta-analysis [166]. The results of this study and previous Swedish studies indicate that prevention based on psychiatric measures alone is probably ineffective, which is why the findings are important to increase the understanding of the mechanisms involved in suicide prevention and to improve CAP clinical practice and society's programs for social support to this group of children and youth. An important challenge doing this has to do with "providing continuity of care as they are often noncompliant and commonly drop out or prematurely conclude their treatment"[167].

It should also be stated that a different approach may be required for the early detection and treatment of patients with early-onset psychosis who are likely to present clinical characteristics associated with a poor outcome [168, 169]. Schwartz and colleagues [170], Remschmidt and co-workers [133] and Schimmelmann and co-workers [171] have all pointed to the need for a longitudinally based diagnostic system for these cases.

## **11.2 PLANS FOR FUTURE RESEARCH**

The results from the former CAP patients treated in paediatrics and in CAP during childhood and adolescence before becoming later patients in GenP will be a starting point for further studies to explore this trajectory towards mental ill health in adulthood.

The quantitative design of this study will be supplemented by a more qualitatively oriented study focusing on the patients themselves and their experiences. This will give a basis for the understanding of which therapeutic mechanisms contribute to the more effective treatments and how these processes progress.

Since the aims of this study did not include the gender perspective and sex differences a future study may be executed to explore the gender perspective and especially differences of importance to understand the variance of vulnerability and resilience within and between the sexes

From the mid 1990s there has been a change in CAP organization where inpatient care has been replaced by different forms of out-patient treatment and specialized units for the age groups 16-25 years. This change rationalizes a new follow up of patients from today's CAP organization and comparison of those new results to the findings presented in this thesis.

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