Ulla Timlin

ADOLESCENT'S ADHERENCE TO TREATMENT IN PSYCHIATRIC CARE
ULLA TIMLIN

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Abstract

The purpose of this study was to investigate treatment adherence among adolescents receiving mental health care, with a special focus on psychiatric inpatient treatment. Key goals were to derive a general definition of adherence suitable for this purpose and to assess adolescents’ adherence to medication and non-pharmacological treatments. This study had two phases; phase one involved conducting systematic literature reviews, and phase two was based on empirical research in which data were collected by analyzing notes on hospital patients. The aim of the reviews were to review current research evidence into treatment adherence in adolescents and factors relating adherence among adolescents receiving mental health care (original publication n=15 and original publication n=17). Phase two was part of a clinical follow-up project called STUDY-70 conducted at the Department of Psychiatry at Oulu University Hospital in Finland. This phase yielded two further original publications – papers III and IV. Paper III examined adherence among adolescents receiving psychiatric inpatient care (n=72), focusing on both medication and non-pharmacological treatments. Paper IV examined factors affecting treatment adherence among these 72 inpatient adolescents, including family- and clinic-related variables.

The systematic reviews demonstrated that many different definitions of adherence have been used in the literature. A concept synthesis was applied to these definitions to establish a basis for empirical research. The main factors that were found to correlate positively with treatment adherence among adolescents were the patients’ own will to be treated and positive sentiments, but family also played an important role. Factors that correlated negatively with adherence included negative feelings, a lack of cooperation with treatment, and adverse mental symptoms. Adolescent who has received special support at school was found to favor treatment adherence, whereas involuntary treatment, self-mutilative behavior and a close maternal relationship were all linked to non-adherence.

Treatment adherence is an ongoing process, and achieving high levels of adherence should be an important goal in all treatment processes. It is important for clinical staff to be aware of factors influencing adherence in order to support the provision of effective and high-quality care for adolescents.

Keywords: adherence, adolescence, inpatient psychiatric treatment, mental health treatment, outpatient treatment
Timlin, Ulla, Psykiatrisessa hoidossa olevan nuoren hoitoon sitoutuminen.
Oulun yliopiston tutkijakoulu; Oulun yliopisto, Lääketieteellinen tiedekunta; Medical Research Center Oulu; Oulun yliopistollinen sairaala; Helsingin yliopistollinen sairaala, Nuorisopsykiatrisen laitos

**Tiivistelmä**


**Asiasanat:** avohoito, hoitoon sitoutuminen, mielenterveyshoito, nuori, psykiatrinen osastohoito
For all teenagers in psychiatric care
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Oulu, April 2015. 

Ulla Timlin
### Abbreviations and Acronyms

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<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>APA</td>
<td>American Psychiatric Association</td>
</tr>
<tr>
<td>DSM-III-R</td>
<td>Diagnostic and Statistical Manual of Mental Disorders, 3rd edition, revised</td>
</tr>
<tr>
<td>DSM-IV</td>
<td>Diagnostic and Statistical Manual of Mental Disorders, 4th edition</td>
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<tr>
<td>EuropASI</td>
<td>European Addiction Severity Index</td>
</tr>
<tr>
<td>GARF</td>
<td>Global Assessment of Relational Functioning</td>
</tr>
<tr>
<td>JBI SUMARI</td>
<td>System for the Unified Management, Assessment, and Review of Information</td>
</tr>
<tr>
<td>KELA</td>
<td>Finland’s Social Insurance Institution</td>
</tr>
<tr>
<td>K-SADS-PL</td>
<td>Kiddie Schedule for Affective Disorder and Schizophrenia for School-Age Children, Present and Lifetime</td>
</tr>
<tr>
<td>PRISMA</td>
<td>Preferred Reporting Items for Systematic Reviews and Meta-Analyses</td>
</tr>
<tr>
<td>OR</td>
<td>Odds ratio</td>
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<td>WHO</td>
<td>World Health Organization</td>
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List of original publications

This thesis is based on the following publications, which are referred throughout the text using the Roman numerals I-IV:


II Timlin U, Hakko H, Heino R & Kyngäs H. Factors relating to adolescent adherence to mental healthcare treatment – A systematic integrative review of the literature. (manuscript)


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1 Introduction

Between them, mental, neurological, and substance use disorders are accounted for 13% of the total global burden of disease in the year 2004. In addition to their debilitating impact in their own right, mental illnesses are associated with elevated rates of disability and mortality, and mental health disorders can exacerbate or be exacerbated by other diseases including cancer, HIV infection or cardiovascular disease (WHO 2014.). In Finland, mental problems were the second most common reason for receiving sickness benefit, accounting for a total of 3.5 million days lost from work in the year 2013 (KELA 2013).

Around one in five children and adolescents suffers from developmental, behavioral or emotional problems, and around one in eight have been clinically diagnosed with at least one mental disorder (Carral et al. 2009). According to Merikangas et al. (2009), around 25% of all youths have experienced a mental disorder, and around one third of all people will experience a mental disorder at some point in their adolescence. Similarly, around 15-25% of adolescents suffer from a mental problem of some sort, the most common of which are depression and behavioral, anxiety, or substance use disorders. The incidence of mental health problems in adolescents is comparable to that in adults and around twice as high as it is in children. Unfortunately, however, only 20-40% of adolescents with mental health problems seek help from mental health organizations (Marttunen & Kaltiala-Heino 2011).

There are several major programs aiming to improve the health of people living in Finland. One of them is Health 2015, a public health programme that aims to improve individuals’ health and functional capacity so that they can lead longer and more active lives, and to reduce the differences between the health outcomes of different groups within the Finnish population (Ministry of Social Affairs and Health: www://http.stm.fi/en/health_2015). In addition, a national development programme for social welfare and health care called KASTE was implemented between the years of 2008-2011 in order to manage and reform social and health policy. One of its key aims was to enhance the provision of healthcare services for children, adolescents and families. (Ministry of Social Affairs and Health: http://www.stm.fi/en/strategies_and_programmes/kaste.) A parallel programme known as the MIELI plan aims to define the main principles and priorities that will guide the provision and development of mental health care and the treatment of substance abuse problems until the year 2015. In addition to providing effective prevention and treatment of mental health problems, this

It is essential to promote mental health among adolescents in order to prevent the development of mental health problems and facilitate their treatment because such efforts contribute to a healthy adolescence and provide a foundation for a healthy adulthood (Knopf et al. 2008). Non-adherence to prescribed treatments is a common and important problem in healthcare (Cooper et al. 2007, Kikkert et al. 2008, Alene et al. 2012) that can lead to poor treatment outcomes and relapse (Alene et al. 2012). However, adherence to treatment is difficult to achieve and the process is influenced by many factors (Steger et al. 2012) including the severity of the patient’s symptoms and their environment (McNicholas 2012). In addition, adherence among adolescents is influenced by their age and developmental stage (Taddeo 2008). It is essential for healthcare staff to recognize the profound impact of adherence on treatment outcomes (Eisenmann 2012, Gearing et al. 2012a). However, assessing adherence to treatment can be challenging (McNicholas 2012).

The purpose of this study was to investigate treatment adherence among adolescents receiving mental health care, with a special focus on psychiatric inpatient treatment. Key goals were to derive a general definition of adherence suitable for this purpose and to assess adolescents’ adherence to medication and non-pharmacological treatments. The study presented in this thesis was conducted in two phases: phase one involved conducting systematic literature reviews, while phase two involved empirical research.

Information on factors relating to adolescent treatment adherence in the exiting literature is rather fragmented. Furthermore, most factors that have been identified relate primarily to medication adherence rather than adherence to non-pharmacological treatment. Only a minority of studies have focused on both adherence to medication and non-pharmacological treatment. To address this gap, literature-based and empirical investigations into medication and non-pharmacological treatment adherence were conducted, yielding some robust and unambiguous conclusions. The thesis is situated in the field of nursing science and is based on both retrospective and applied research.

The following section of the study presents an overview of the literature on adherence among adolescents and was based on the literature searches that
underpinned the systematic literature reviews reported in original publications I and II. However, the overview does not discuss the papers included in the systematic reviews. Instead it describes the studied phenomena in more general terms, including a brief description of the ways in which adolescents differ from children and adults.
2 Adolescent’s adherence to psychiatric treatment

2.1 Adolescents in psychiatric care

2.1.1 Defining “adolescent”

The Oxford English Dictionary (2014) states that an adolescent is a person in the age of adolescence. Mosby’s Medical & Nursing Dictionary (1986) defines adolescence as the developmental period between the onset of puberty and adulthood, which usually occurs between the ages of 11-13 and 18-20. During this period, the individual undergoes physical, psychological, emotional and personality changes. It is a key period in the development of the individual’s identity and self-conception, and in the movement toward independence from parents. Consequently, adolescents usually want to make their own decisions. Adolescents’ capacity for abstract thought increases as they age, and in social terms they usually want to be part of a peer group (Adelman & Ellen 2002, Christie & Viner 2005, Taddeo et al. 2008). Key processes that typically occur during adolescence are biological maturation, the development of personal identity, acclimatization to sexuality and intimacy with appropriate partners, and the development of independence and autonomy within the prevailing sociocultural environment (Christie & Viner 2005). Adolescents’ cognitive, social, emotional and physical capacities are not fully developed because they are still growing beings (Claveirole 2004). It is therefore important to thoroughly understand normal adolescent development patterns in order to implement effective health care regimes for patients at this stage of development (Adelman & Ellen 2002).

2.1.2 Mental illness

Key indicators of good mental health and criteria for assessing mental health are: 1.) a positive attitude toward oneself, 2.) growth, development and self-actualization, 3.) integration, 4.) autonomy, 5.) reality perception, and 6.) environmental mastery. These criteria are not absolute; each person has limits and no one achieves all of the criteria perfectly, but it is possible to approach the optimum. Good mental health cannot be defined in simple behavioral terms
because the definition of good mental health varies between individuals and depends on one’s life situation (Stuart 2001a). Defining mental health and illness can therefore be controversial. It has been argued that mental illness does not exist at all because its symptoms can be explained by diseases of the brain or life problems. Conversely, some believe that almost any deviation from common or “normal” behavior should be regarded as a mental disorder. While there are many different definitions of mental disorder, they all have a common strand and a person is considered to be mentally disordered if their psychological capacity is diminished relative to typical members of their peer group (Varelius 2009, Marttunen & Kaltiala-Heino 2011).

When assessing adolescents’ mental states and mental disorders, it is essential to consider some unique aspects of adolescence. First, adolescents are continuously growing and changing. Second, most childhood mental disorders are expressed via an excessive tendency to display behaviors commonly exhibited by young people, such as aggression or dieting. Lastly, mental health issues among adolescents are often linked to their familial relationships (Scott 2004). Moreover, adolescents have a distinct combination of sensitivity and vulnerability because they are at a developmental stage where they are seeking to adopt a more independent posture and leave behind their former intense dependency on their parents. This presents a series of emotionally challenging dilemmas, which can provoke aggressive responses, non-adherence, sullenness, or withdrawal. Some adolescents negotiate these issues without trouble but many do not. In addition, adolescents can understand the meaning of an illness whereas children cannot (Kurtz et al. 2010). There are many mental disorders that first arise during adolescence (Murphey et al. 2013) and may continue in adulthood (Marttunen & Kaltiala-Heino 2011). It has been reported that one in five adolescents experiences significant emotional distress or some form of mental disorder (Knopf et al. 2008, Marttunen & Kaltiala-Heino 2011), and almost one in ten are emotionally impaired (Knopf et al. 2008).

2.1.3 Treatment and treatment culture

Mental health services must be readily obtained; ease of access is essential for an effective mental health system. A comprehensive mental health care system should offer multiple points of entry for treatment (including self-referral) and a variety of providers. Mental health care systems have traditionally been divided into private sector / public sector and outpatient / inpatient services. (Stuart
It is considered best to provide outpatient mental health services as a first option but treatment in a psychiatric hospital may be required if the patient’s mental symptoms are severe (Mental Health Act 1116/1990). In particular, inpatient treatment is required if the patient’s mental state and condition are deteriorating rapidly or outpatient treatment fails to achieve adequate improvement, necessitating intensive observation (Luk 2004).

**Treatment in Finland**

According to Finland’s Mental Health Act (1116/1990) mental health work involves promoting the patient’s mental health and well-being, ability to cope, and personal growth. It also encompasses preventing, curing, and alleviating mental illnesses and disorders. Mental health care is administered via mental health services, which are provided for individuals suffering from diagnosed mental illness or other mental disorders. Such care and services should primarily be organized on an out-patient basis and in a way that encourages the patient to voluntarily seek treatment. However, patients suffering from a severe mental illness or disorder must be provided adequate treatment and services with appropriate medical care and social rehabilitation (Mental Health Act 1066/2009).

Under the terms of Finland’s Health Care Act (1326/2010), municipalities must organize mental health services within their borders as part of their public health obligations. Moreover, hospital districts offering specialized medical care must provide such care to all individuals requiring it within their catchment area. Hospital districts that contain university hospitals must provide all forms of specialized medical care that may be required within their catchment area.

**2.1.4 Inpatient treatment for adolescents**

The Mental Health Act of Finland (954/1990) stipulates that inpatient services for minors should only be provided in hospital wards designed for children and adolescents, and that such young patients must be treated separately from adults. This law prompted an increase in the number of psychiatric inpatient hospital beds for children and adolescents during the 1990s. By international standards, Finland has a large number of inpatient hospital beds for children and adolescents (Ellilä 2007). Adolescent psychiatric treatment in Finland is currently provided by the country’s Health Districts, and is treated as a medical specialty in its own right, which is not the case elsewhere in Europe (Marttunen & Kaltiala-Heino 2011, ...
Adolescent mental health care encompasses both inpatient and outpatient treatment, but is mainly provided via outpatient polyclinics (Marttunen & Kaltiala-Heino 2011). However, current national recommendations emphasize the development of community-based outpatient services for adolescents (Karukivi et al. 2013, Pylkkänen 2013). It has been noted that the number of adolescent outpatient care periods per year has increased by 68% since 2006 (Fredriksson & Pelanteri 2014), in keeping with trends observed in other countries (Geller & Biebel 2006, Meagher et al. 2013).

The most common mental health conditions observed in adolescents are anxiety disorders, affective disorders, eating disorders, adaptive disorders, asociality, substance use, psychotic symptoms, and suicidality (Ellilä 2007, Marttunen & Kaltiala-Heino 2011). In addition, adolescents suffering from conduct / oppositional disorders and developmental disorders may be treated at inpatient facilities (Ellilä 2007). Depression was the most widely diagnosed mental health issue among adolescents in 2011, and most adolescent mental health inpatients during this year were girls (Fredriksson & Pelanteri 2014).

Inpatient treatment in psychiatric mental health care is based on a personal treatment relationship with a clinician / named nurse, and patients interact constantly with other adolescents and adult healthcare professionals. Inpatient treatment usually involves therapeutic treatment groups together with occupational and music therapy. However, hospital-based schooling is also provided and linked closely to activities occurring in the inpatient ward. Inpatient treatment offers wide-ranging opportunities for assessing and individual’s mental symptoms and behavior, and for providing medical treatment. (Marttunen & Kaltiala-Heino 2011.)

**Involuntary treatment**

Involuntary treatment methods and the most restrictive restraint procedures such as seclusion and mechanical restraint are only used with the most disturbed inpatients as methods of last resort (Ellilä 2007, Hottinen et al. 2013). Several control and restraint techniques have been developed to provide alternatives to these extremely restrictive methods. Involuntary treatment may be required to achieve long-term improvement in the patient’s mental state and to prevent the severe degradation of quality of life that psychiatric illness can cause (Vuckovich 2010). Different European countries have different laws governing involuntary psychiatric treatment (Jendreyschak et al. 2014), and there may also be variation
at the federal or regional level (Ellilä et al. 2008, Jendreyschak et al. 2014). Most adolescents subjected to involuntary psychiatric treatment suffer from psychotic disorders, substance use disorders, or suicidality (Ellilä et al. 2008). In general, the likelihood of involuntary restraint increases with an individual’s history of aggression and number of previous placements. Multi-factorial models that account for diverse individual and contextual factors have been developed to predict the probability of an adolescent experiencing at least one period of involuntary restraint (Tompsett et al. 2011).

According to Finland’s Mental Health Act (1116/1990) a patient may only be treated against their will if they are diagnosed as being mentally ill, their mental state would deteriorate significantly without treatment and cause them to severely endanger their own health or that of others, and other mental health options would be ineffective or inadequate. However, comparing to adult, a minor can be ordered to psychiatric hospital treatment against own will if the person is seriously mentally disordered with other requirements (Mental Health Act 954/1992).

### 2.1.5 Treatment and the influence of the outside environment

Both genetic and environmental factors affect adolescents’ mental health treatment and therefore influence the treatment process. Environmental factors can be divided into factors relating to family, school and friends. (Maughan 2004.) Adolescents are closely linked to their families, and family life factors have profound effects on the treatment of adolescent mental health patients (Scott 2004, Miklowitz et al. 2008, Brinkman et al. 2009, Khaleque 2013, Lewis et al. 2013, Schueler & Prinz 2013). Notably, the feelings and responses of the patient’s parents have important effects on treatment outcomes (Rasaratnam et al. 2004, Pellerin et al. 2010). Cooperation with family and parents is therefore essential (Maughan 2004). It should be noted that children from single parent or step families exhibit higher levels of emotional and behavioral problems than children from non-divorced two-parent families (Scott 2004, Laukkanen et al. 2013). In addition to family-related factors, adolescents’ relationships with their friends play vital roles in their lives; typical adolescents are estimated to spend twice as much time with their friends as they do with their parents or other adults. Social rejection can provoke feelings of loneliness and reduce the availability of support that would otherwise mitigate stressors. Rejection by friends and peers has been
linked to poor school performance and drop-out as well as the incidence of psychiatric disorders (Maughan 2004).

School plays a central role in adolescents’ lives and presents a unique set of demands and challenges. A major role of schooling is to promote socialization. Consequently, starting at a new school represents a major life event that is very demanding and potentially troublesome (Maughan 2004). School-related mental health problems may be expressed in different ways; they may lead to poor school performance or behavioral issues at home. Regardless, adolescents suffering from mental problems or illnesses should be given the opportunity to study at their own school insofar as possible, and support should be made available within schools to allow this to occur (Marttunen & Kaltiala-Heino 2011). School personnel and teachers should collaborate closely with healthcare professionals to ensure that this support is provided because it plays an essential reconstructive role in the treatment of adolescent mental health issues (Rose et al. 2009, Marttunen & Kaltiala-Heino 2011). Teachers are increasingly aware of the difficulties faced by adolescents with mental illnesses and are keen to help them, but there is still a need to develop optimized teaching methods and provide special school services for such pupils, particularly those undergoing inpatient treatment (Laukkanen et al. 2013). Overall, health care professionals of inpatient ward are constantly integrating with different individual, family and social environment levels (Maughan 2004, Ellilä 2007).

### 2.2 Adherence to treatment

#### 2.2.1 Adherence

There are many definitions of adherence in the literature, and the meaning of the term often depends on the context in which it is used. The Oxford English Dictionary (2014) defines adherence as follows: 1. attachment to a person, party, or cause; steadfast support; loyalty, allegiance, 2. a group of adherents or supporters, 3. the action or process of physically adherent to something; the action or fact of sticking fast or of sticking together, 4. an associated quality, property; an adjunct, an accompaniment and 5. something that adheres to an object or surface. The World Health Organization (WHO) introduced a definition that was agreed by the participants of the WHO Adherence meeting in 2001, according to which adherence is “the extent to which the patient follows medical instructions”
According to McNicholas (2012), adherence can be regarded as a non-judgmental process that assumes a clinician-patient relationship based on partnership and mutual respect. In mental health and psychiatric treatment, adherence can be seen as a voluntary behavior whereby the patient acts to implement collaboratively established treatment recommendations provided by the treatment staff (Vuckovich 2010).

Adherence to pharmacological treatment is the extent to which the patient takes the medication as prescribed (Kikkert et al. 2008, Alene et al. 2012); it can be defined in binary terms as the case where a patient takes their medication as prescribed at least 75% of the time (Levy et al. 2012, Steger et al. 2012). For non-pharmacological treatments, adherence can be defined by measuring the patient’s attendance at treatment sessions, scheduled appointments, and therapy (Wang et al. 2000, Alvarez-Jimenez et al. 2009, Agyapong et al. 2010). Alternatively, it can be defined in terms of a behavioral continuum reflecting the extent to which a patient follows through with prescribed treatments (Shaw 2001). Cooper et al. (2007) divide adherence into two separate components: persistence and compliance. Finally, Longhofer & Floersch (2010) describe adherence among adolescents as a non-steady state phenomenon that is produced on a moment-to-moment basis as the patient confronts the desires of others.

2.2.2 Related concepts

The most widely used concepts similar to adherence are compliance, persistence, and therapeutic alliance. However, terms such as concordance, engagement and continuity of care have also been used to describe phenomena with similarities to adherence. Compliance can be understood as accordance with the prescribed treatment (Cooper et al. 2007), and carries the implication that the person may have been forced, coerced, pressured, or persuaded to accept it (Vuckovich 2010). In some respects, it can be seen as an agreement that has not been established jointly between both parties (McNicholas 2012). Persistence can be defined as the duration of the period between the initiation and discontinuation of treatment (Cooper et al. 2007, Assayag et al. 2013), and therapeutic alliance is a relationship between the treatment staff and patient that encourages the patient to believe that the staff are interested in their wellbeing and know how best to promote that wellbeing (Vuckovich 2010). Langhoff et al. (2008) argue that a high level of patient cooperation and trust is required to establish therapeutic alliance, and that a robust therapeutic alliance has four key components: 1.) the
therapist-patient alliance (TPA), which relates to the therapist’s perception of their
encounters with the patient; 2.) the patient-therapist alliance (PTA), which reflects
the patient’s perception of these encounters; 3.) the mutual therapeutic alliance
(MTA), which relates to an external third party’s perception of the encounters
between therapist and patient; and 4.) and the therapist-patient concordance
(TPC), i.e. the degree of overlap between the perceptions of the patient and the
therapist.

Concordance can be defined as the extent to which the patient’s goals for
their treatment align with those of the staff, which should ideally be almost
complete and harmonious (Vermeire et al. 2001, Vuckovich 2010). High levels of
concordance are likely to promote adherence (Longhofer & Floersch 2010).
Treatment engagement is a multifactorial concept that encompasses the
acceptance of the treatment, therapeutic rapport and collaboration towards a
shared goal of both functional and clinical recovery (MacBeth 2013). Zheng et al.
(2013) assessed service disengagement by counting the number and type of
contacts maintained between case managers and patients. Joyce et al. (2014)
examined attendance at follow-up appointments for similar purposes, but
discussed their results in terms of “continuity of care” rather than engagement.
Continuation can be defined as continuously following a prescribed treatment
regimen over a certain period of time (Bhowmik et al. 2013).

2.2.3 The concept of “adherence” in the present study

Of the concepts discussed in the preceding section, the two that have been most
widely used in the literature are compliance and adherence (Vermeire et al. 2001).
However, “compliance” assumes that the patient accepts the instructions of the
treatment staff (Ioasa-Martin & Moore 2012) and agrees to take medication
without arguing (Vuckovich 2010). It thus implies a rather paternalistic approach
(Vermeire et al. 2001). In contrast, “adherence” allows the patient a more active
role and the ability to choose whether or not to follow the instructions they are
given (Isoa-Martin & Moore 2012). Adherence can be applied to both medication
pharmacological and non-pharmacological treatments (McNicholas 2012) and for
the long-term benefit of severely and seriously mentally ill patients, promoting
treatment adherence should be a major goal (Vuckovich 2010). It is argued that
the term adherence is recommended to use when discussing these issues
(Vermeire et al. 2001, Ioasa-Martin & Moore 2012). In this work, the term
adherence is used to describe the studied phenomenon and to encompass all of the
related concepts discussed in the preceding paragraphs. Treatment adherence is understood to refer to both medication and non-pharmacological treatments.

### 2.2.4 Methods for assessing treatment adherence

Literature searches indicate that adherence to medication has been studied more extensively than adherence to non-pharmacological treatment. Medication adherence is typically assessed by means of pill counts (Nakonezny et al. 2010, Talley 2011, Levy et al. 2012), medical/pharmacy records or chart reviews (Gearing & Charach 2009, Prukkarone et al. 2010, Bhowmik et al. 2013, Joyce et al. 2014), clinician ratings, medication diaries, self-reports, or urine/blood tests (Nakonezny et al. 2010). Questionnaires can also be used to assess medication adherence (Ibrahim 2002, Gearing & Charach 2009, Longhofer & Floersch 2010, Wong et al. 2011).

Adherence to non-pharmacological treatment (especially attendance of scheduled appointments, follow-up treatment sessions, or therapy) has been investigated based on patients’ files and medical records (Lolomon & Evans 1992, Lazarou et al. 2006, Charupanit 2009, Agyapong et al. 2010, Conus et al. 2010, Moscrop et al. 2012, Joyce et al. 2014). Questionnaires and certain scales have also been used for this purpose (Wang et al. 2000, Diamond et al. 2002, MacBeth et al. 2013, Moore et al. 2013, Murphy et al. 2013, Zheng et al. 2013). Adherence to therapy has been investigated by functional assessment (Gaynor et al. 2006) and by counting appointment attendance (Alvarez-Jimenez 2009).

### 2.3 Treatment adherence among adolescents

This section describes previous studies on treatment adherence among adolescents including studies that had some adolescent participants but did not focus exclusively on adolescent issues. In such cases, information concerning adolescents was generally not separated from that relating to other patients, so the results of these investigations are presented in terms of “patients” or “clients” rather than adolescents specifically. Most of these studies examined adolescent (i.e. individuals who were at least 14 years old) and adult patient groups, but some dealt with adolescents and children. The results of studies that focused exclusively on adolescents are presented using the term “adolescence”.

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2.3.1 Prevalence of adherence to non-pharmacological treatment

Many studies on mixed populations (i.e. populations including adolescents and other age groups) have reported low rates of adherence to non-pharmacological treatment, which is a common problem in mental health care (Stevens et al. 2006, Adeponie et al. 2007, Charupanit 2009, Agyapong et al. 2010, Conus et al. 2010, Pellerin et al. 2010, Moscrop et al. 2012, MacBeth et al. 2013, Zheng et al. 2013, Gearing et al. 2014). However, reasonably good treatment adherence rates have been found. Thus, according to Adeponie et al. (2007), 5% of patients failed to attend scheduled appointments. Similar results were reported by Conus et al. (2010), who found that 23% of patients eventually disengaged from their recommended treatment regime, and by Zheng et al. (2013) who found that 14% of patients were nonadherent to non-pharmacological treatment and failed to attend scheduled appointments. Charupanit et al. (2009) also reported good rates of treatment adherence, with only 21% of patients being nonadherent to scheduled psychiatric appointments.

Cases with higher levels of non-adherence include that reported by Agyapong et al. (2010), in which only 56% of patients were adherent to psychiatric follow-up treatment. Similarly, only 56% of adolescents were adherent to cognitive-behavioral therapy homework tasks (Gaynor et al. 2006), and Lazaratou et al. (2006) found that most patients (59%) were non-adherent to therapy.

Unfortunately, Gearing et al. (2009) reported that over a two-year follow up period, 20% of patients experienced relapse requiring hospital readmission, with 33% being readmitted within a year of their original admission and 44% being readmitted within two years.

2.3.2 Prevalence of adherence to medication treatment

Adherence to prescribed medication regimes is important but several studies have reported relatively high nonadherence rates, which presents a major challenge for treatment (Shaw 2001, Hassan et al. 2007, Charach et al. 2008, Prukkanone et al. 2010, Talley 2011, Offord et al. 2013). It can be challenging for adolescents to adhere to medication regimes, and for treatment staff to influence nonadherence (Eisenmann 2012).

Offord et al. (2013) found that 60% of patients quickly became nonadherent to medication, with a mean time to discontinuation of only 20 days. Prukkanone et al. (2010) obtained similar results, with only 23% of patients being fully adherent
to prescribed medication regimes. Lloyd et al. (1998) found that 38% of patients were adherent to medication treatment. However, Sawada et al. (2009) reported more positive results, suggesting that 56% of patients were adherent and Ibrahim (2002) observed adherence rates above 70%. In studies focusing exclusively on adolescents, Talley (2011) reported an adherence rate of 76% for pharmacological treatment, while Gearing & Charach (2009) reported that only 25% of adolescents were non-adherent.

2.3.3 Factors affecting treatment adherence

Non-pharmacological treatment

According to McNicholas (2012), successful treatment requires the patient to understand and believe that they are ill, and to therefore wish to follow the recommended treatment. In addition, the patient must have positive expectations for the treatment. This is also true for the parents of children who are undergoing treatment. Non-adherence to non-pharmacological treatment is associated with increased psychopathology and poorer premorbid social adjustment in mental health patients (MacBeth et al. 2013), as well as more severe functional impairment (Pellerin et al. 2010) and increased symptom severity (Pellerin et al. 2010, Murphy et al. 2012, MacBeth et al. 2013). In particular, non-adherence has been linked to increased severity of depression (Gonzales et al. 2011). Conus et al. (2010) reported that have found that the patient’s treatment history and severity of baseline symptoms both affected treatment adherence, as did living alone. Substance use during treatment has been linked to non-adherence (Wu et al. 2001, Conus et al. 2010, Scivoletto et al. 2012). In addition, adherence is promoted in adolescent patients who have some understanding of their illness (Parellada et al. 2009, McNicholas 2012). Conversely, poor understanding of illness and untreated psychosis have been linked to poor adherence to cognitive-behavioral therapy (Alvarez-Jimenez et al. 2009).

Attendance at scheduled appointments was improved when patients regularly talked about their feelings (Murphy et al. 2012). In addition, prior outpatient treatment and adherence to prescribed psychotropic medication regimes were associated with good continuity of care (Joyce et al. 2013). In addition, previous contacts with psychiatric services have been linked to better attendance at follow-up psychiatric appointments (Agyapong et al. 2010), and living with family
members has likewise been connected to improved treatment adherence (Scivoletto et al. 2012). Service disengagement has been linked to low levels of patient education (Zheng et al. 2013) as well as certain types of therapist, the presence of non-welfare clients, and living more than 50 km away from the treatment location (Charupanit 2009).

Among adolescents, continuity of care is most likely to be disrupted when dealing with older patients and patients living in rural areas (Joyce et al. 2014). Parents’ perceptions of their child’s mental health service needs have also been linked to treatment adherence in adolescents (Wu et al. 2001). Similarly, Stevens et al. (2006) found that the quality of the therapist-family relationship and perceived relevance of treatment influenced treatment dropout rates. Finally, parental distress and depressive symptoms have been linked to treatment adherence among adolescents (Pellerin et al. 2010).

Medication treatment

Remission of mental symptoms has positive effects on adherence to prescribed medication treatment (Steger et al. 2012) whereas ongoing substance abuse is predictive of illness relapse (Levy et al. 2012). Lloyd et al. (1998) report that general nonadherence to discharge plans followed by post-discharge substance use are negatively associated with general treatment adherence. In addition, poor relationships with the individual prescribing medication, experiences of coercion during admission to treatment (Day et al. 2005) and limited understanding of one’s own condition (Day et al. 2005, Wong et al. 2011) have been linked to negative attitudes towards treatment and non-adherence. Vourakis (2005) identified substance use as a risk factor for treatment non-adherence, along with major depression and multiple psychiatric diagnoses. Medication adherence among adolescents was improved when prescriptions for atypical antipsychotics were combined with medicines intended to treat affective symptoms (Gearing & Charach 2009). In a study on adherence to prescribed lipid-lowering medication, negative overall attitudes to medication and perceived obesity were associated with non-adherence (Wong et al. 2011). Adherence to medication can be improved by interventions designed to address beliefs, behaviors and relationships associated with adherence (Iosa-Martin & Moore 2012). According to McNicholas (2012), patients need to understand the importance of their medication and its impact must be explained clearly in a way that allows the patient to understand the outcomes they can expect.
2.4 Health care professionals’ influence on treatment adherence

Long waiting times to receive help and access to mental health services are common reasons for treatment nonadherence. Families in particular are more likely to be nonadherent if they face long waiting times. (Westin et al. 2014.) Gearing et al. (2012a) studied techniques for promoting adherence that have been adopted by healthcare researchers and divides them into three classes: outreach, concrete and motivational. The most widely used outreach promoters were telephone calls to remind patients of upcoming sessions and discuss missed appointments, which were used by 52% of researchers. Concrete promoters or incentives were used by 57% of researchers; the most common incentives offered were paid travel expenses. However, the most widely used techniques were motivational promoters, which were employed by 70% of researchers. When considering these results, it should be noted that most of the studied researchers were examining ongoing therapeutic interventions. It has also been suggested that the promotion of implementation intentions may be an effective way of addressing negative feelings about treatment and improving adherence to psychotherapy (Sheeran et al. 2007). Jungbluth et al. (2013) found that therapeutic homework adherence among adolescents could be improved by giving them a strong rationale for completing the work, increasing the amount of time available for its completion, eliciting reactions and troubleshooting obstacles.

Patient education was also reported to be useful in promoting adherence to medication among adolescents and their families (Eisenmann 2012). Likewise, clinical interventions that incorporate education and provide services to support adolescents and their families and encourage medication adherence have positive long term effects on adherence. (Gearing et al. 2009). Among adults, medication adherence could be improved by periodically sending out ‘reminder’ short message service (SMS) text messages (Montes et al. 2012). A similar result was obtained in a study featuring both adult and adolescent participants (Branson et al. 2013). In addition, junior psychiatrists who were trained in adherence therapy exhibited an enhanced awareness of potential causes and consequences of nonadherence, and therefore made greater efforts to empathize with patients in order to promote adherence (Surguladze et al. 2002).

Overall, there are many methods for improving treatment adherence, and the optimal methods may differ for adult, adolescent, and child patients. When working with adolescents, it is important to involve their family members and parents in their treatment. In addition, it is important to correctly assess the
patient’s level of adherence in order to properly understand their situation (McNicholas 2012).

2.5 Importance of adherence to treatment

Nonadherence to treatment has personal, societal, and economic consequences (McNicholas 2012). It can lead to relapse of illness and repeated hospitalizations, which are costly and ineffective (Vuckovich 2010). Medication nonadherence has been linked to hospital readmission among adolescents (Goodpastor & Hare 1991, Fontanella 2008, Gearing et al. 2009). This imposes severe costs adolescents exhibiting disruptive behaviors are particularly likely to be rehospitalized (Chung et al. 2008).

According to Beecham et al. (2009), the mean cost of a single admission in the UK was £24,120, although costs vary widely. In Finland, psychiatric illnesses were judged to be the most costly of all extra expensive treatments performed in Finland during 2004, consuming over 68 million euros or 38% of the extra treatment budget (Sennilman & Pekurinen 2005). Adolescent psychiatric inpatient treatment is estimated to cost 3500€ per week (Heinonen et al. 2012). It is therefore important to identify cost-effective methods for improving adherence (Branson et al. 2011), both to promote improved treatment outcomes and to avoid the expense of readmission (Surguladze et al. 2002, Charupanit 2009, Pellerin et al. 2010) In addition nonadherence to treatment due to mental illness has severe long- and short-term effects on adolescents (Block & Greeno 2011, MacBeth et al. 2013). Attention must be paid to factors linked to treatment disengagement because maintaining engagement is vital (Conus et al. 2010). In general, poor adherence to treatment will lead to symptom recurrence (Charach et al. 2008).

2.6 Summary of the literature

Definitions of adherence in the literature vary, and the definition used in any given case will be influenced by the context under consideration. Consequently, there is no universally accepted definition. The identification of a robust general definition of adherence that is suitable for use when studying adolescents receiving mental health treatment (and especially inpatient treatment) was therefore a key early goal of the study presented in this thesis. Overall, research on treatment adherence has largely focused on adults rather than adolescents, and
most of the existing research on adolescents’ deals with medication adherence rather than adherence to non-pharmacological treatment.

Treatment adherence among adolescents is influenced by family and environmental factors such as the actions of their friends and the support available at school. In addition, clinical factors and the adolescent’s mental state have important effects. While the literature does contain important information on treatment adherence among adolescents, it is scattered across multiple publications and there is a need for summarizing it to a single resource. Nevertheless, the results mentioned in the preceding sections clearly demonstrate that poor treatment adherence can have severe adverse effects on adolescents with mental health problems. Nonadherence affects the patient’s personal and social life, and may lead to relapse and hospital readmission. This is costly, wasteful, and detrimental to the patient’s mental health. In extreme cases, readmission could lead to very costly and detrimental involuntary treatment that could have been avoided if better treatment adherence measures had been in place (Fig. 1).
Fig. 1. Summary of literature findings concerning treatment adherence among adolescents.
3 Aims of the study

The purpose of this study was to investigate treatment adherence among adolescents receiving mental health care, with a special focus on psychiatric inpatient treatment. Key goals were to derive a general definition of adherence suitable for this purpose and to assess adolescents’ adherence to medication and non-pharmacological treatments. This study had two phases; phase one involved conducting systematic literature reviews, and phase two was based on empirical research. The specific aims of each phase were:

Phase one

1. To review current research evidence into treatment adherence in adolescents and the available data about factors relating to adolescents’ adherence to mental health treatment.
   a.) to identify how adherence was defined in each study (Original publication I)
   b.) to summarize the studies’ findings concerning adolescents and treatment adherence (Original publication I)
   c.) to identify which factors relate positively or negatively to adolescents’ adherence to their treatment (Original publication II)

Phase two

2. To examine adherence among adolescents in psychiatric inpatient, focusing on both medication and non-pharmacological treatments.
   a.) how well do under-aged adolescents adhere to mental health treatments, and what are the factors that affect adherence? (Original publication III)

3. To examine inpatient adolescents’ adherence to medicinal and non-pharmacological treatments in general and individual, with a special attention to associated, contributing factors that originate within the family and the clinic.
   a.) to evaluate the proportion of adolescents adhering to treatment (Original publication IV)
   b.) to find out which family and clinical factors relate to adolescent non-adherence (Original publication IV)
4 Methodology

4.1 Retrospective and mixed methods research design

The original publications presented in this study were based on a retrospective design using mixed research methods because they focused on previously published research articles and inpatients’ hospital case notes that were prepared at specific points in time in order to investigate treatment adherence among adolescents and factors affecting it. Retrospective research is based on data that is already available and provides unique opportunities for analysis (Junod & Elger 2010). A retrospective approach can be used to identify risk factors for different levels of a problem or condition and makes it possible to identify specific factors that contribute to a given phenomenon and dissect their effects (Polit & Beck 2012). Because both the proposed cause and the proposed effect have already occurred, they can be analysed simultaneously (Burns & Grove, 1997). In this study, the treatment of the studied adolescents had already been completed and they had been discharged from the hospital. Their recorded levels of treatment adherence were therefore investigated to identify commonalities among subjects that may have influenced their adherence or non-adherence. According to Vassar & Holzmann (2013) retrospective chart reviews are generally applicable research tools that use readily available data and can be used within the clinical sciences to guide and inform subsequent prospective investigations. Both phases of this study, i.e. the systematic literature reviews (Original publications I and II) and the empirical research (Original publications III and IV) are based on the data that were examined retrospectively.

A multidisciplinary mixed research methods approach was adopted in this study to provide a comprehensive overview of the investigated phenomena. Mixed methods designs give researchers powerful tools for studying complex, multidimensional processes in health care (Fetters et al. 2013) and permit the combined use of varied quantitative and qualitative techniques. This provides a range of different opportunities to address the research problems. (Creswell & Plano Clark 2011, Gelling 2014.) Understanding complex processes, systems or experiences are essential to nursing and health care. Therefore, both quantitative and qualitative approaches have been used to provide rich knowledge of healthcare experiences using different designs and methods. (Larkin et al. 2014).
However, mixed methods approaches also present challenges that must be considered carefully. There are four widely used general mixed methods research designs: exploratory, explanatory (Creswell & Plano Clark 2011, Polit & Beck 2012, Fetters et al. 2013), triangulation and embedded designs. In an exploratory design, qualitative data are gathered during an initial phase followed by quantitative data. In an exploratory design, the reverse data collection order is used. A triangulation design uses a complementary approach in which both data types are collected simultaneously and given equal priority. Finally, embedded designs use one type of data (either qualitative or quantitative) to support analyses based primarily on the other type; either data type may be “dominant” in such a design (Creswell & Plano Clark 2011, Polit & Beck 2012).

An exploratory design was used in this study, with qualitative data being gathered first (and used in original publications I, II and III) followed by quantitative data (used in original publications III and IV) in order to achieve a more comprehensive and detailed exploration of the studied phenomenon. In addition, original publication III described a mixed-methods study in which qualitative data were collected and analysed in conjunction with quantitative information. Finally, findings derived from qualitative data (original publications I and III) were used to guide the design of the second phase of the quantitative research (original publication IV), and some findings based on qualitative data (original publication II) were directly linked to the subsequent quantitative study (original publication IV). The conceptual framework for the empirical investigations presented in this thesis was developed based on the two systematic literature reviews and the method for classifying adherence that was developed from the reviews. The bulk of the data collected in this study was qualitative, so qualitative methods (used in original publications I, II and III) were more heavily used than quantitative methods (original publications III and IV). The general design of the study is presented in Fig. 2.

Two key aims were kept in mind during the qualitative analyses. The first was to systemically gather high quality research information about adolescents’ adherence to medication and non-pharmacological treatment and to present in a condensed form with supporting analysis in order to provide a solid foundation for subsequent empirical investigations (original publications I and II). The second key aim was to gather and analyse a detailed dataset on adherence to prescribed medication and non-pharmacological psychiatric treatment among inpatient adolescents in order to describe the studied phenomenon (original publication III). These findings informed and guided subsequent quantitative data
gathering. The first phase of this study culminated in the publication of two systematic literature reviews on both outpatient and inpatient adolescents who use mental health services. This breadth of coverage demonstrate the comprehensive nature of the investigation and provided a robust background for the empirical research of phase two.

Fig. 2. Study design.

4.2 Subjects and settings

The first phase (original publications I and II) was based on two systematic literature reviews. The purpose of systematic review is to identify, critically evaluate and synthesize all of the existing literature on the topic of interest (Khan et al. 2003, Cronin et al. 2008). Systematic reviews can be regarded as an independent method (Dixon-Woods et al. 2007, Cronin et al. 2008) and are used to obtain information about well-focused questions concerning clinical practice (Cronin et al. 2008). Therefore they are a key element of evidence-based healthcare (Khan et al. 2003). In this study, systematic reviews were conducted by searching four major literature databases (MEDLINE, CINAHL, COCHRANE,
PsycINFO) for reports published between 1990 and 2014 describing empirical research into mental health treatment adherence among adolescents.

The second phase (original publications III and IV) constitutes the empirical part of the investigation, and is based on data gathered from patients’ hospital records. The resulting original publications (III and IV) are part of a clinical follow-up project called STUDY-70, which examined hospital-treated underage adolescents with severe psychiatric disorders and the relationships between various psychosocial risk factors. The data used in the STUDY-70 project were collected between 2001 and 2006 from the Department of Psychiatry at Oulu University Hospital in Finland. The studied population included inpatient adolescents (n=637) aged 12-17 years who were first admitted to Unit 70 at the Department of Psychiatry at Oulu University Hospital between April, 1, 2001 and March, 31, 2006 (i.e. patients whose index hospitalization occurred between these dates). Of the 607 eligible adolescent patients, 508 (83.7%) chose to participate in the STUDY-70 project. As shown in figure 2, the following patients were excluded: patients over the age of 18 (n=1), adolescents with intellectual disabilities (n=26) or organic brain disorders (n=3), patients with overly short inpatient periods (n=22), and adolescents who did not give their written informed consent to participate or whose guardian(s) refused on their behalf (n=77).

The population sample that was suitable for the purposes of Studies III and IV consisted of 81 adolescents whose subsequent treatment, after acute index hospitalization, continued without pause in another ward of the same hospital. Adolescents were excluded from these investigations if their subsequent treatment was carried out in a children’s psychiatric ward (n=5) or if they did not receive the intended treatment after leaving the acute admission ward (n=4). Thus, the final sample consisted of 72 adolescents whose treatment continued in either closed or open adolescent psychiatric wards at Oulu University Hospital (Fig. 3).
Fig. 3. Sampling process used in this study.
Background information on inpatient treatment among participating adolescents (III, IV)

Of the 72 adolescents whose records were examined in original publication III, 71% (n=51) were female and 57% (n=57) were 16 to 17 years old; the mean age of the studied patients was 15.47. The most common treatment period was up to three months (44%, n=32). Adolescents were recommended one or more of the following treatments, depending on their mental state: 1. medication, 2. therapy, 3. psychological examination, 4. occupational therapy, 5. music therapy, 6. sessions with a named nurse, 7. physiotherapy, 8. family meetings, 9. collaboration meetings, 10. visits to a follow-up treatment site, or 11. other treatment, such as neurological examination or rehabilitation (Table 1).

<table>
<thead>
<tr>
<th>Background information</th>
<th>n</th>
<th>%</th>
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<tbody>
<tr>
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<tr>
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</tr>
<tr>
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<td>16-17</td>
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<tr>
<td>Treatment time*</td>
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<td></td>
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</tr>
<tr>
<td>Over 12 months</td>
<td>6</td>
<td>8</td>
</tr>
</tbody>
</table>

*Information on the treatment status and treatment time variables were gathered from hospital case notes

4.3 Procedures, data collection and analysis

4.3.1 Phase one; systematic literature reviews (I, II)

Qualitative methods were used to investigate definitions of treatment adherence among adolescents, to summarize existing findings concerning adolescents’
treatment adherence, and to identify factors known to influence treatment adherence. Data were collected from four electronic databases: CINAHL, MEDLINE, COCHRANE and PsycINFO. The search terms were defined by the author in collaboration with an information specialist and were as follows:

a.) Subject headings: patient compliance, treatment compliance, mental disorders, psychiatric hospitals, psychiatric nursing, psychiatric nurses, psychiatric patients, psychiatry, adolescent psychiatry, preventive psychiatry, community psychiatry, psychoanalysis, psychosomatic medicine, adolescence

b.) Other search terms: adheren*, therapeutic alliance, cooperate*, cooperati*, co-operati*, complian*, adolescen*, teen*, young

Searches for both of the systematic reviews were conducted on the 1st of April 2011, after which the analytical processes that culminated in original publications I and II were initiated. This is the search date quoted in original publication I. However, an updated search was conducted on the 9th of September 2014 to ensure that the analysis presented in original publication II was based on the most up-to-date published information about factors affecting treatment adherence in adolescents. Therefore, the total number of search results reported in original publication I was 715 while that for original publication II was 1042. The search process was conducted by two researchers (UU, HK).

The updated search process and the subsequent review of the newly identified papers revealed three new relevant papers that were added to the final analysis in original publication II. However, one paper that had been included in the first analyzed set was excluded from the second systematic review because its inclusion and exclusion criteria made it unsuitable for the latter analysis. Therefore, whereas the analysis in original publication I was based on 15 literature reports, that in original publication II was based on 17 (Fig. 4).

The hits from the initial searches were subjected to quality appraisal conducted by two researchers to assess the relevance of their contents to the research questions posed in each review, and to assess the quality of the studies they described. The quality appraisal was based on the JBI-SUMARI package validity checklists (Pearson et al. 2009), which were used as an aid in the critical assessment of studies. These checklists include a set of standard critical appraisal instruments for specific study designs, which are built into the analytical modules of the JBI SUMARI software package (the Joanna Briggs Institute, 2008).
Fig. 4. Details of the search processes (original publications I and II).

Analysis (I, II)

A narrative approach was used in the data analysis of the first two original publications concerning the systematic literature reviews because the gathered data were insufficiently homogeneous to enable statistical pooling for the purpose of meta-analysis. A narrative approach was chosen because it was appropriate for
the research focus and the content of the studies of the systematic review (Polit & Beck 2012). A narrative approach was required because the reviews were based on both qualitative and quantitative studies. A narrative approach is a technique that groups different qualitative and quantitative studies based on different pieces of research evidence into more homogenous groups (Lucas et al. 2007). These systematic reviews involve integrating data and findings from studies conducted using diverse approaches and therefore can be considered being integrative systematic reviews (Flinkman & Salanterä 2007, Polit & Beck 2012).

The data analyzed in original publication I were initially extracted based on the aims of the investigation. Narrative synthesis was then performed on all 15 included studies in order to identify all of relevant information. The aim was to obtain detailed information from each of the included studies in a condensed form (Polit & Beck 2012). Further, based on all the definitions of adherence reported in the previous research articles, the results of the analysis were used to synthesize general definitions of full adherence, partial adherence and non-adherence.

The data examined in original publication II were analyzed using thematic analysis which is a focused process for identifying, organizing, analyzing, and presenting themes within diverse data sets (Braun & Clarke 2006). Thematic analysis is a form of pattern recognition that seeks to find themes in a text at different levels and further categories for analysis (Attride-Stirling 2001, Federay & Muir-Cochrane 2006). The analysis was undertaken as follows: first, all relevant information was identified; second, this information (sentences) was listed; third, it was coded and summarized into more simple forms; fourth different codes were grouped into themes; and finally these themes were reviewed and refined to identify the major factors affecting adherence among adolescents.

Background information on all analyzed papers is presented on Table 2 (original publications I and II).

<table>
<thead>
<tr>
<th>Authors</th>
<th>Purpose</th>
<th>Context of the treatment</th>
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<tbody>
<tr>
<td>Bernstein et al. (2000) (I, II)</td>
<td>To investigate medication compliance</td>
<td>Outpatient</td>
</tr>
<tr>
<td>Bobier &amp; Warwick (2005) (I, II)</td>
<td>To identify factors associated with readmission</td>
<td>Inpatient</td>
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<tr>
<td>Coletti et al. (2005) (I, II)</td>
<td>To describe medication adherence and examine relations</td>
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</tr>
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<td>DeBellero et al. (2007) (I, II)</td>
<td>To examine the outcome of following an initial hospitalization</td>
<td>Outpatient, inpatient</td>
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<tr>
<td>Fontanella et al. (2011) (II)</td>
<td>To examine rates of antidepressant</td>
<td>Outpatient, inpatient</td>
</tr>
<tr>
<td>Authors</td>
<td>Purpose</td>
<td>Context of the treatment</td>
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<tr>
<td>--------------------------</td>
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<tr>
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<td>To estimate prevalence of medication noncompliance</td>
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<td>Granboulan et al. (2001)</td>
<td>To study short-term compliance with follow-up care</td>
<td>Outpatient</td>
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<td>King et al. (1997)</td>
<td>To study family predictors of compliance with treatment</td>
<td>Outpatient</td>
</tr>
<tr>
<td>Moses (2011)</td>
<td>To examine medication commitment, experiences with medication and factors associated to commitment</td>
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<tr>
<td>Munson et al. (2010)</td>
<td>To explore the adherence behaviors in treatment</td>
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<td>Patel et al (2005)</td>
<td>To compare longitudinal use of psychotropic medication</td>
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<td>Pereira et al. (2006)</td>
<td>To examine the role of therapeutic alliance in predicting treatment dropout, response and outcome</td>
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<td>Pogge et al. (2005)</td>
<td>To examine postdischarge adherence to medication</td>
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<td>Schimmelmann et al. (2006)</td>
<td>To assess the risk and predictors of service disengagement</td>
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<td>Stewart &amp; Baiden (2013)</td>
<td>To examine factors associated with medication nonadherence</td>
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<td>Townsend et al. (2009)</td>
<td>To evaluate medication attitudes and predicting adherence</td>
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<td>Woldu et al. (2011)</td>
<td>To examine relationship between adherence and both clinical response and suicidal events</td>
<td>Outpatient</td>
</tr>
</tbody>
</table>

### 4.3.2 Phase two; empirical research (III, IV)

The adherence of inpatient adolescents, including both medication and non-pharmacological treatment, with particular emphasis on associated and contributing familial and clinical factors, were examined in two empirical researches. These empirical original publications (III and IV) are part of the STUDY-70 project, which focuses on adolescents (n=508) admitted for treatment.
in a psychiatric ward. In total, 72 of these 508 adolescents were found to be eligible for the empirical studies presented in this study.

**Original publication III**

For original publication III, data were collected from hospital case notes written by the treating physician at discharge. The discharge reports had been written at the end of the adolescent patient’s treatment period and included information on the entire course of the treatment process. Data analysis was initiated while reading the discharge summary from the hospital case notes and collecting the relevant information.

The data analysis for original publication III had two phases. In the first phase, the data were analyzed by using inductive content analysis to describe and organize the information within (Elo & Kyngäs 2008). This approach is suitable for studying unstructured written material (Mayring 2000, Elo & Kyngäs 2008, Polit & Beck 2012) such as the final discharge reports analyzed in this study. Content analysis permits the systematic and reproducible compression of many words in a text into a much smaller number of content categories based on well-defined coding rules (Stemler 2001). At first the collected data was reviewed thoroughly and all of the relevant information was identified. This information was then listed in a separate sheet and each piece of information was condensed into a few words and then grouped with related pieces of information to form categories. The categories were defined by combining related topics and content areas. Individual categories were then named and summarized based on their contents. In the second phase, the number of items within each category was counted, subject to the restriction that in any given category, only one item per adolescent was counted. For the purposes of quantification, variability is expressed numerically in terms of the extent to which an attribute is observed (Polit & Beck 2012). To this end, the number of adolescent subjects whose records contained references to each sub-category was calculated and expressed as a percentage of the overall number of subjects.

**Original publication IV**

In original publication IV, the adolescent participants were first classified into two categories: adherent or non-adherent with respect to medication and non-pharmacological treatment. Information on their adherence was collected from the
case notes describing their treatment in the hospital. Hospital case notes included documents prepared by both doctors and treatment staff. The final definition of adherence used was based on the investigated definitions from the analyzed papers of original publication I and on the results and conclusions concerning adolescent adherence from original publication III. An initial synthesis yielded three adherence categories (original publication I). The description of adherence among adolescents presented in original publication III (which examined the same group of adolescents studied in original publication IV) was then added to the adherence categories reported in the literature. The resulting adherence classification table, which featured three distinct categories (full adherence, partial adherence, and non-adherence) was then simplified by removing the “partial adherence” classification and moving some of the elements used to define partial adherence into the full adherence category and others into the non-adherence category. During the classification process the researcher kept detailed notes of the decisions made concerning adolescents’ classification during the study, allowing the classification table to be checked on an ongoing basis. The final classification criteria were thus confirmed while the classification was being performed.

After the initial classification had been completed, each studied adolescent was further classified with respect to the nature of their (non)-adherence, yielding four statistical dependent variables: 1.) adherent / non-adherent to medication treatment, and 2.) adherent / non-adherent to non-pharmacological treatment. Among the patients classified as being adherent to medication treatment were eight adolescents who were not prescribed any medication during their inpatient period. The decision to classify these patients as adherent was made in cooperation with the clinician. These variables were further coded to describe the extent of the patients’ adherence: 3.) partial treatment adherence (indicating adherence to either medication or non-pharmacological treatment, but not both, and 4.) adherence to all referred treatment (i.e. both medication and non-pharmacological treatment). The resulting dataset featuring four dependent variables was transferred into IBM SPSS (Statistical Package for Social Science) Statistics, version 20.

To identify factors and background variables that correlated with (non)-adherence to different prescribed treatments, variables such as age, gender and specific clinical variables (n=18) and family variables (n=19) for each adolescent were transferred from the STUDY-70 project data. Information on these variables was gathered from interviews with the adolescents conducted according to the
semi-structured Schedule for Affective Disorder and Schizophrenia for School-Aged Children, Present and Lifetime (K-SADS-PL) during the adolescent’s period of treatment (Kaufman et al. 1997). These interviews were conducted by a trained medical student under supervision or by the treating physician. The European Addiction Severity Index (EuropASI) interview was also used to assess familial and clinical factors and was performed by the staff nurse (Kokkevi & Hartgers 1995). Information on involuntary treatment (including continued observation as part of voluntary treatment, n=16), and treatment duration was also included in the statistical analyses. Data on these two variables were collected from original publication III.

Analysis (IV)

The analysis presented in original publication IV had two phases. First, the relationships between the background variables and outcomes were analyzed by cross-tabulation and the significance of the identified relationships were tested either by Pearson’s $\chi^2$-test or by Fisher’s exact test. Second, a step-wise binary logistic regression analysis was used to find significant predictors of non-adherence. Fisher’s exact test is an alternative to Pearson $\chi^2$-test for the 2x2 table; it is most useful and more appropriate than the $\chi^2$-test when the sample sizes and expected cell frequencies under consideration are small (Forthofer et al. 2007, Munro 1997). Logistic regression analysis is a technique that describes the relationships between a set of independent variables and dependent variable. It yields a predictive equation and is used to predict categorical dependent variables. (Munro 1997, Forthofer et al. 2007, Polit & Beck 2012).

The variables chosen as predictors for the construction of logistic regression models were the adolescents’ age and gender, and all variables linked to non-adherence with a p-value of ≤ 0.2. In addition, variables were included if they were conceptually related to other variables having a p-value of ≤ 0.2. For example, if a variable relating to friends’ or parents’ substance abuse problems was selected, other factors relating to social/familial relationships and substance abuse would also be included.

Non-adherence (as opposed to adherence), was used as an outcome variable in the statistical analyses. A stepwise logistic regression analysis was conducted to examine the association of familial and clinical factors with adolescents’ non-adherence. Stepwise selection using the Forward LR method was used to identify
variables to be included in the final logistic regression model (Table 3 and 4 in Appendix).

4.4 Ethical considerations and personal involvement

No consent or permission was required or sought prior to conducting the literature reviews conducted during phase one of this study. However, all of the appropriate regulations and guidelines were adhered to during the entire research process, from data collection to data analysis and reporting. The ethical conduct of research requires careful study design, with particular regard for the participants’ interests, benefits, risks, and confidentiality (Working Group for the Study of Ethical issues in International Nursing Research & Olsen 2003).

The STUDY-70 project was approved by the Ethical Board of the University hospital (11.4.2001, 44/2001) and the participants (i.e. the adolescents and their parents/guardians) all gave written consent to participate. Informed consent is a crucial ethical aspect of mental health research (Hoop et al. 2008, Fouka & Mantzorou 2011, Siriwardhana et al. 2013). Therefore the phase two studies (original publications III and IV) required the approval of the organization in charge of the Study-70 project (Oulu University Hospital, Department of Psychiatry). In addition, the researcher was given written permission by the administrative medical director of Oulu University Hospital to access patients’ case files for research purposes. The identities of the adolescent subjects were not explored and patient medical records were not transferred.

The researcher did not make any copies of the case files and so the analysis was based entirely on hand-written notes made while examining the files. These notes contained no specific information about the participants such as names, ages, specific treatment times, or names of their treatment site in order to ensure patient anonymity. To address privacy concerns, when the data were transcribed into electronic form, they were stored on a computer secured with a password known only to the researcher. These safeguards are important to ensure the confidentiality of the participants’ information. To permit the discussion of individual participants without identifying them by name, each participant was assigned a unique code (Orb et al. 2000, Fouka & Mantzorou 2011, Siriwardhana et al. 2013). All of the permission and consent forms were stored in a locked closet to which only the researcher had a key. By these methods, the anonymity of the participants in the empirical studies (III and IV) was ensured.
The author of this study has been accorded permission to use data from the STUDY-70 project. Even though the author did not participate in the data gathering process of STUDY-70, she did contribute to the design of the studies presented in the original publications. The author conducted all of the searches underpinning the systematic literature reviews in collaboration with an information specialist (RH), and conducted the subsequent quality appraisals together with a second researcher (HK). In addition, the author personally analyzed the data generated during the systematic reviews, collected the qualitative data for original publication III, and analyzed it individually. All of these processes were reflected on and discussed with the author’s research group. The statistical analyses presented in original publication IV were designed and conducted by the author together with a statistical expert (HH). In addition, the author wrote the first and final versions of all of the original publications, was the corresponding author for all four publications, and coordinated the correction and resubmission processes of each one.
5 Results

5.1 Investigation and definition of adherence (I, II, III, IV)

Thirteen out of the eighteen publications examined in the two systematic reviews (original publications I, II) investigated adolescents’ adherence to medication treatment. Most (15) of these studies were based on outpatient data. In nine (60%) studies data were collected via questionnaires. A further seven (47%) used patient interviews, and five were based on medication / pill counting or information collected from patients’ records / files. Three (20%) studies counted attendance at therapy / scheduled appointments or blood tests. Nine (60%) of the studies included self-reported information provided by the adolescent undergoing treatment, eight (53%) featured data gathered by mental health professionals, and seven (47%) featured information provided by a parent or other responsible adult.

Original publication I gathers and synthesizes existing definitions of adherence. The results of this synthesis were further developed in original publication III, leading to the final definitions of adherence and non-adherence that were presented in original publication IV and used to classify adolescents as adherent or non-adherent to different types of treatment. The final definition is presented below and the key elements used to assess adherence among inpatient adolescents are italicized.

Adherence: The patient attends majority of the scheduled appointments, completes a majority of the prescribed treatment, and stops only with the consent of the treatment team; and/or the patient takes the medication at least 75% of the total number of times recommended by the physician in the absence of external pressure. If possible, the patient is considered medically and psychiatrically asymptomatic and stable upon discharge. The adolescent is cooperative and willing to: receive treatment despite symptom severity, participate actively, and put effort into working with caregivers to relieve their mental symptoms or illness.

Non-adherence: The patient discontinues medication without medical advice or fails to take medication as prescribed, and/or the patient refuses contact with the treatment facility, is untraceable, or discontinues treatment sessions. The patient is unmotivated, uncooperative or unwilling to receive treatment, even when attending a session, and expresses this to the staff.
After the final update and analysis presented in original publication II, three new studies with different definitions of adherence were identified. These definitions are presented below:

1. Adherence is indicated by an MPR (medication possession ratio) of 80% or more (Fontanella et al. 2011).
2. Non-adherence is defined as taking less than 80% of the prescribed medication during the month prior to admission, or refusing to take some or all of the medications prescribed in the 3 days preceding the assessment (Stewart & Baiden 2013).
3. Nonadherence is defined as having at least one plasma drug concentration of zero, or a twofold or greater variation in the LDR between the two assessment points. Adherence is defined as the consumption of at least 70% of the prescribed medication (Woldy et al. 2011.)

These three definitions, which were not considered in the syntheses presented and used in original publications (I, II, III, and IV) were resynthesized, leading to a definition of adherence as taking at least 70% - 80% of the prescribed medication and non-adherence as refusal to take medication or having at least zero or twofold variation in plasma drug concentrations between successive assessment points. These new, updated elements are consistent with the definitions created based on the earlier synthesis, which thus remain valid.

5.2 Treatment adherence among adolescents and related factors (II, III, IV)

Based on the systematic literature review (original publication I) full adherence to non-pharmacological treatment was reported in six studies (40%) and in eight (53%) of the studies, 34% – 67% of the adolescents were fully adherent to medication. Similarly, most of the inpatient adolescents examined in the empirical research of this study (78%, n=56) adhered to medication treatment and non-pharmacological (61%, n=44) treatment. No medication was prescribed for eight of the adolescents. There were no significant gender or age differences for these adherence types: 76% (n=16) of boys and 78% (n=32) of girls adhered to their prescribed medication regimes, as did a majority of both age groups considered: 12-15 years (74%, n=23) and 16-17 years (80%, n= 33). Further, 71% (n=15) of boys and 60% (n=29) of girls, and 58% (n=18) of adolescents aged 12-15 years
and 63% (n=26) of those aged 16-17 adhered to non-pharmacological treatment (original publication IV).

Adherence among inpatient adolescents was reflected by co-operation, active participation and willingness to undergo treatment (original publication III). Adherent adolescents were quite likely to acclimatize to the prescribed treatment (36%, n=26), form bonds with other adolescents (28%, n=20) and participate in ward activities (24%, n=17). Adherent adolescents also agreed to follow-up pharmacological and non-pharmacological treatments (71%, n=51), attended ward treatment groups (33%, n=24) and voluntarily reported their own symptoms to clinicians or treatment staff (31%, n=22). Adherent adolescents were also willing to plan their treatment in collaboration with clinicians and treatment staff (18%, n=13), and to undergo follow-up treatment (17%, n=12). Adherence also had some appreciable effects on health and wellbeing, including symptom relief (47%, n=34), perceived helpfulness of medication (30%, n=21), school attendance (30%, n=21) and more active socialization (22%, n=16).

The factor that correlated most strongly with treatment adherence among adolescents was the patient’s belief in the effectiveness of their treatment, which instilled a desire to receive treatment (original publication II). This is reflected in positive cooperation by the adolescent, a positive attitude to medication treatment, and intense engagement with both medication and non-pharmacological treatments. Other factors linked to adherence included the perceived helpfulness of medication and adherence to medicine / non-pharmacological treatment with elements of effectiveness. It should be noted that all of these factors have to do with outpatient treatment.

According to original publication IV, above all, special services at school appears to predict better adherence to both medicine and non-pharmacological treatment among inpatient adolescents (partial treatment OR 0.16, p=0.027; medication treatment. OR 0.15, p=0.022; non-pharmacological treatment OR 0.30, p=0.054; all referred treatment OR 0.30, p=0.026). A well-functioning family environment (as reflected by a high GARF score) also correlates positively with both forms of treatment adherence. Therefore, adolescents who can access special services and support at school, and have strong functional familial relationships are most likely to be adherent to treatment.
5.3 Treatment non-adherence among adolescents and related factors (II, III, IV)

Based on the results of this investigation, non-adherence to medication and non-pharmacological treatment among adolescents is reflected in opposition and a negative attitude to treatment (original publication III). Non-adherent adolescents appeared to defy their prescribed treatment (21%, n=15) or to be disobedient (11%, n=8) and absent from the ward without permission (11%, n=8). In addition, non-adherent adolescents often refused either inpatient treatment (18%, n=13) or follow-up treatment (11%, n=8). Also, 10% (n=7) expressed a negative attitude toward medication.

Mental symptoms, limited functional capacity, and social sensitivity represent key challenges to medication and non-pharmacological inpatient treatment of non-adherent adolescents (Study III). Particularly severe challenges were associated with delusional ideas (28%, n=20), strong mental symptoms at the beginning of the treatment (22%, n=16), depressive symptoms (21%, n=15), poor concentration (22%, n=16) or aggressive behavior (15%, n=11). In addition, 15% of adolescents (n=11) exhibited no insight into their condition. Further, many adolescents had difficulties in social situations (21%, n=15) or in interacting with others (25%, n=18), and some were reclusive (19%, n=14). Difficulties in following planned courses of treatment (19%, n=14), low motivation to persevere with treatment (15%, n=11), and an inability to cope with one’s personal situation (14%, n=10) were all reflective of a limited ability to function.

The factors that contribute most heavily to treatment nonadherence among adolescents are adverse life situations and a lack of close relationships. However, illness and negative feelings towards treatment are also important (original publication II). Low cohesion among friends and relatives, including a lack of solidarity with family members and close friends, appear to have particularly strong adverse effects on treatment adherence among adolescent outpatients. Other important factors include youth, pronounced symptoms of illness (especially those associated with certain diagnoses) and readmission. Negative feelings about the side-effects of medication and the perception that medication is unhelpful both contribute to nonadherence to medication treatments, as does the perception that medication is not required. All of these factors other than readmission relate to outpatient treatment.
The analysis presented in original publication IV suggested that the strongest predictor of nonadherence (to all forms of treatment) was a history of involuntary treatment, which is particularly strongly linked to nonadherence to non-pharmacological treatment (OR = 5.60, p = 0.004). Self mutilative behavior was also predictive of non-adherence to non-pharmacological treatment (OR = 4.76, p = 0.010) and all referred treatments, including medication and non-pharmacological treatment (OR = 6.86, p = 0.006). A close maternal relationship also appeared to be predictive of nonadherence to all referred treatments (OR = 6.86, p = 0.049).

5.4 Summary of findings

Based on the results of these investigations, new studies on medication adherence and adolescents receiving outpatient treatment have been initiated. In previous studies, adherence was normally assessed using instruments / questionnaires or patient interviews. Definitions of adherence used in the literature vary, but some common elements can be discerned, enabling a synthesis to create a general definition.

Adherence among inpatient adolescent is reflected by positive co-operation, active participation and willingness to receive treatment. Most adolescents are adherent to treatment. A key factor in adherence is the adolescent’s voluntary acceptance of and desire for treatment, which is associated with positive feelings towards treatment. Strong familial relationships and cohesion, and special services at school also contribute positively to adherence. The major challenges to adherence stem from the mental symptoms of inpatient adolescents, social sensitivity and a poor ability to co-operate. Negative feelings towards treatment (and especially medicinal treatment) also correlate negatively with adherence. A history of involuntary treatment and self-mutilative behavior are particularly strongly linked to non-adherence to all forms of treatment. Nonadherent inpatient adolescents are typically opposed to all forms of treatment and have negative feelings about their treatment (Fig. 5).
Fig. 5. Summary of results.
6 Discussion

6.1 Overview of the results

The purpose of this study was to investigate treatment adherence among adolescents receiving mental health care, with a special focus on psychiatric inpatient treatment. Key goals were to derive a general definition of adherence suitable for this purpose and to assess adolescents’ adherence to medication and non-pharmacological treatments. This study proceeded in two phases, involving systematic literature reviews followed by empirical research. The results obtained shows that the concept of adherence is multidimensional and that its definitions in the literature vary. In addition, there are many similar concepts describing same elements. The literature generally reports fairly low rate of adherence among adolescents in mental health or psychiatric care, which is consistent with the empirical results presented in this study to some extent. However, the overall adherence rates observed were quite good.

Information on factors relating to adolescent treatment adherence in the exiting literature is rather fragmented. Furthermore, most factors that have been identified relate primarily to medication adherence rather than adherence to non-pharmacological treatment. Only a minority of studies have focused on both adherence to medication and non-pharmacological treatment. To address this gap, literature-based and empirical investigations into medication and non-pharmacological treatment adherence were conducted, yielding some robust and unambiguous conclusions.

Overall, the conceptual framework for the empirical investigation was developed on the basis of the systematic literature review and the associated system for classifying adherence. The phase one included an analysis of literature data on adolescents’ treatment adherence in mental health care, while phase two built on the conclusions of phase one to assess treatment adherence in psychiatric inpatient care

The discussion of results is based on studies with adolescent study subjects, contrasting to children and adults. In addition the text of the discussion is using a term “patient” when the information generally describes the phenomenon or is based on adults.
6.1.1 Adherence to treatment

Medication adherence

Based on the systematic literature review (original publication I) adolescents were found to be adherent to medication in eight (53%) of the studies, with reported adherence rates of 34%-67%. However, the empirical investigations indicated that most (78%) of the inpatient adolescents on the studied ward were adherent to medication treatment, and adherence was not significantly affected by either gender or age (original publication IV).

The results obtained in this study are consistent with literature data. Talley (2011) found that self-reported rates of medication adherence among adolescents were 94%; the corresponding rates based on caregiver reports and pill counting were 93% and 94%, respectively. Further, Gearing et al. (2009) found that 77% of outpatient adolescents were adherent to medication treatment. In addition, studies that included adolescents suggested that only 25% of outpatients relapsed after receiving medicinal treatment (Gearing & Charach 2009, Levy et al. 2012). Joyce et al. (2013) found that nearly half (49.5%) of all adolescents were adherent during the acute treatment phase and 42% remained adherent afterwards. However, Sawada et al. (2009) reported that only 44% of outpatients continued their medication treatment for 6 months and overall 56% of patients were found to be adherent.

Nakonezny et al. (2010) found similar rates of adherence among inpatient adolescents. They used multiple methods to study medication adherence among children and adolescents receiving acute care. The adherence rates depended on the method used: electronic monitoring suggested a rate of 87.5%, pill counts yielded a rate of 90%, parents’ diaries suggested a rate of 93%, and patient diaries indicated rates of 93%. These results can be compared to those reported by Kikkert et al. (2008) for medication adherence among inpatient adults. Based on three different instruments, these authors determined adherence rates of 55% from a self-reported questionnaire, 20%, based on clinicians’ assessments, and 14%, based on a self-reported questionnaire on drug attitudes. In a different study, 67.5% of adult outpatients remained under treatment after one year of follow-up, with 79% remaining adherent to medication treatment (Cooper et al. 2007).

The rates of inpatient adherence observed in this study (original publication IV) were appreciably higher than those identified in the systematic review (original publication I). This difference may be because the empirical research
dealt with inpatients whereas the literature studies primarily related to outpatients; inpatients may be more adherent in general. However, it is also worth noting that literature studies on inpatient adults and youths suggest that the latter tend to have higher adherence rates, at least for medication treatment.

**Non-pharmacological adherence**

Adolescents were found to be adherent to non-pharmacological treatment in six studies (40%). Treatment was administered in the form of therapy, outpatient appointments, or in a psychiatric ward or center (original publication I). A majority (62%) of inpatient adolescents were adherent to non-pharmacological treatment in this study and no significant relationship between (non)-adherence and age or gender could be identified (original publication IV).

These results are similar to those reported in the literature on adolescent adherence. According to Adeponle *et al.* (2007) 68% of patients turned up for their scheduled appointments and Agyapong *et al.* (2010) found that 56% of patients adhered to follow-up appointments. Similarly, another study reported adherence rates of 49% for outpatient appointments (Gonzales *et al.* 2011). On the other hand, 21% missed scheduled appointments (Charupanit 2009) and 23% of patients disengaged from service (Conus *et al.* 2010). In addition, 27% missed at least one scheduled treatment (Adeponle *et al.* 2007).

It is interesting to compare the reported adherence rates for adolescents to those for adults. Wang *et al.* (2000) studied adherence to non-pharmacological treatment in 11 different countries and found an overall adherence rate of 83%, with the inter-country range being 76% - 96%. Interestingly, this suggests that adults are more adherent to treatment than adolescents. In addition, it should be emphasized that the adolescent inpatient investigated in this study had lower rates of adherence to non-pharmacological treatment than to medication treatment (original publication IV). This may be because medication is easy to take on a routine basis and is taken under the supervision of the treatment staff on the ward. It is thus simpler and requires less effort on the patient’s part than participation in non-pharmacological treatment.

**Adherence among inpatient adolescents**

Adherence among inpatient adolescents was reflected by co-operation, active participation and willingness to undergo treatment. Conversely, nonadherence
was reflected in opposition to treatment and negativity toward treatment (original publication III). As mentioned before, the adherence rates of adolescent inpatients to medication treatment was fairly high (original publication IV) and better than the rates reported in systematic review of this study. Most of the studies included in the systematic review investigated outpatient adherence to both medication and non-pharmacological treatment (original publication I). It should be emphasized that people with mental illness often describe recovery as a journey whose aim is to achieve autonomy and greater participation in normal life as well as activities such as education and employment.

However, many people with mental illness live in a manner inconsistent with recovery due to unemployment, stigma, victimization and vulnerability to homelessness. People with mental illnesses who live in the community require clinical assistance that provides shared decision making and support. (Drake et al. 2014.) Adolescents in the community are similarly and actively embedded in peer, school and family contexts, so physicians who prescribe medication to adolescents are competing for influence with people who interact with the adolescent on a daily basis (Charach et al. 2008). The need to recover and participate in normal day to day activities can thus have important effects on treatment adherence among outpatient adolescents. Adolescents may also be subject to other environmental challenges to recovery. Kruse & Rohland (2002) found that the period between discharge from inpatient care and the commencement of adherence to follow-up treatment is critical but challenging for adult patients. Mojtabai (2010) has investigated sociocultural perspectives on the stigma of mental illness among European populations and found out that willingness to seek professional help is influenced by stigmatizing attitudes. If there is a belief that mental illness is blameworthy and someone with mental illness lives in such a community, their willingness to seek professional help will be reduced. On the other hand, a belief that mentally ill individuals are dangerous or unlikely to recover may increase the patient’s willingness to seek help.

Interestingly, inpatient adolescents’ adherence to non-pharmacological treatment was also good, but less so than their adherence to medication treatment. Day et al. (2005) have reported that the patients’ attitudes toward medication influence their adherence. A need to take medication may conflict with the typical adolescent desire for autonomy (Shaw 2001). Alternatively, taking medication while receiving inpatient care is simple for most adolescents and may be done automatically without much thought. Moreover, inpatients are continuously assessed by treatment staff (Leon et al. 2007, Delaney et al. 2008), which may
influence their adherence to medication treatment, especially because their medicine intake is monitored by the treatment staff.

Adolescents who were taking antidepressants in addition to some other psychotropic medication were more likely to receive and continue with follow-up care (Joyce et al. 2013). This is consistent with the findings presented herein, which indicated that adolescents’ rate of combined adherence to medication and non-pharmacological treatment, i.e. simultaneous adherence to both treatment types, was around 60% (original publication IV). The overall adherence of the studied adolescents was thus good. Sutherland & Harkness (2007) similarly investigated children and adolescents in a psychiatric inpatient unit and concluded that mentally ill children and adolescents require the physical safety offered by the institution but must also be encouraged to show self-efficacy and social development. Inpatient children and adolescents are constantly in groups and following a planned schedule. However, the inpatient unit staff are required to provide support and structure for patients with different and varied needs (Delaney & Hardy 2008), which could have positive effects on treatment adherence. According to Ellilä et al. (2007), there are five prevalent ideologies associated with the provision of nursing care in psychiatric inpatient wards for children and adolescents: family-centered and individual care, milieu-centered care, integrated care, educational care and psychodynamic care. In addition, Delaney (2006) discussed ten interventions that are used to treat children and adolescents in inpatient psychiatric units, which can be divided into three categories: 1.) behavioral interventions, whose goal is to change behavior by altering reinforcement pattern; 2.) affective interventions, whose goal is to influence the regulation of feelings and responses; and 3.) cognitive interventions whose goal is to change the patient’s way of thinking and responding. Overall, health care staff must monitor and assess adolescents on a continuous basis to effectively relieve mental symptoms but they can also influence the recovery of the adolescent’s mental state in several different ways, all of which can have positive effects on treatment adherence. Adolescents deserve an environment in which treatment staff intervene only after careful assessment of their intervention’s likely effects (Delaney 2006).

6.1.2 Factors relating to adherence

Information relating to factors affecting treatment adherence in the literature is distributed across a number of different publications. It was therefore essential to
perform a systematic literature review in order to collect this information (original publications I and II) for analysis and provide a solid foundation for the empirical research of this study (original publications III and IV).

The results of this investigation suggest that the adolescent’s own desire for and acceptance of treatment strongly supports treatment adherence (original publication II). This result is consistent with the finding that cooperation, active participation and willingness to undergo the treatment are key elements of adherence among adolescent inpatients. Delaney (2006) has reported similar results, noting that one important task of psychiatric treatment teams is to help adolescents to achieve control over their feelings and behaviors in order to resolve their mental symptoms and crises. Patient’s beliefs and behaviors have similarly been linked to adherence by McNicholas (2012). Vuckovich (2010) highlights the importance of encouraging the patient to become an active member of the treatment team. This is consistent with the finding that inpatient adolescents’ social sensitivity and poor ability to cooperate were associated with treatment non-adherence (original publication III). Patients are more likely to engage with therapy if they are motivated to change (Moore et al. 2013).

Functional familial relationships and cohesion are also important for treatment adherence among adolescents (original publications II, IV). A lack of cohesion and solidarity with family members and close friends appears to have negative effects on treatment adherence (original publication II). This finding is consistent with the results presented in original publication IV, which indicated that strong and functional familial relationships support adolescent treatment adherence. Perlick et al. (2004) states that patients’ treatment outcomes are adversely affected when their caregivers are burdened by other matters. Similarly, children’s adherence to treatment is reportedly influenced by their parents’ responses (Schueler & Prinz 2013). One of the key results arising from this study was that a close maternal relationship appeared to be associated with non-adherence to both medication and non-pharmacological treatment among adolescents (original publication IV). It has previously been reported that maternal warmth and affection correlate with psychosocial adjustment and personality in children (Khaleque 2013). While adolescents are usually keen to assert their independence and autonomy (Christie & Viner 2005, Taddeo et al. 2008), it is possible that adolescents who have close maternal relationships have not yet entered this developmental stage and therefore find it challenging to be separated from their parents on the ward. However, it is impossible to draw firm conclusions about this correlation because the relationships between the
background variables were not investigated. Therefore, it is not known if adolescents with close maternal relationships came from comparatively dysfunctional families, or whether a strong maternal relationship correlated with any of the other interpretative factors considered. Nevertheless, it is clear that the adolescent’s familial situation affects their adherence; this is also demonstrated by the observation that adherence to therapy is much stronger among adolescents whose parents live together (Lazaratou 2006). Esbjorn et al. (2008) states that psychiatrically ill children are less likely to live with both of their biological parents. However, no significant correlation between adherence and living with one parent, both parents, or in foster care was identified in this study.

Adolescents are surrounded by their family when at home, but they also spend a lot of time in school, so the school environment and teachers also play important roles in adolescents’ lives (Kidger et al. 2010). This supports the result of this study, which indicated that adolescents who had received special services at school before hospitalization are more adherent to treatment (original publication IV). However, it should be noted that this conclusion is based on adolescents’ situation when admitted to hospital after receiving special services at school, and does not necessarily indicate receipt of special services during inpatient treatment. One aim of special services in school is to support the education of adolescents with learning difficulties or mental illnesses (Rose et al. 2009). It is thus possible that adolescents who have received special services at school may already have adjusted to receiving special support and supervision, and is thus not put off by the ward supervision team’s constant assessment and supervision. Effective adolescent psychiatric treatment requires teachers and treatment teams to cooperate closely to ensure that educational goals are achieved while ensuring that adolescents with mental health problems are adequately supported in school (Rose et al. 2009).

Non-adherence

Adolescent’s mental symptoms can reduce adherence to treatment (original publication II, III). This result is continent with literature data: adolescents who failed to complete treatment were reported to exhibit greater impairment of functioning and psychiatric symptoms (Pellerin et al. 2010) and higher levels of comorbid symptoms (Gonzales et al. 2011). The same trend has been found in studies where adults were investigated (Centorrino et al. 2001, MacBeth et al. 2013). However, it has been reported that there is a negative correlation between
baseline levels of illness severity and service disengagement among adolescents and adults (Conus et al. 2010). It has also been suggested that distress is associated with increased endorsement of negative attitudes and that talking to a therapist may help to relieve this issue by helping the patient to better understand their own thoughts and feelings (Murphy et al. 2013). In keeping with these observations, the literature review indicated that adolescents’ negative feelings about medication treatment correlated negatively with treatment adherence (original publication II). Negative feelings may be caused by unpleasant side-effects of medication, a lack of motivation to continue with prescribed medicinal treatment, or a lack of insight into the treatment’s purpose (McNicholas 2012). Elkington et al. (2012) suggest that stigma and labeling may adversely affect treatment engagement, and there is still a need to reduce the stigmatization of service users (Eisenberg et al. 2012). Medication adherence may also be reduced by a perceived lack of treatment efficacy (Steger et al. 2012). In addition, inconsistent levels of recovery have been linked to stigmatization (Drake & Whitley 2014).

Psychotic disorders, suicidality and substance use have all been linked to the involuntary restraint and psychiatric treatment of adolescents in Finland (Ellilä et al. 2008). In addition, Jendreyschak et al. (2014) studied a large cohort in Germany and found that adolescents with substance use problems, psychotic disorders and admission on duty time were at highly elevated risk of involuntary treatment, with every fourth such patient being confined in this way. The results presented herein also suggest that involuntary treatment is strongly predictive of non-adherence to treatment (original publication IV). However, Rain et al. (2003) states that perceived coercion among adult patients is not associated with treatment adherence. For patients that are adherent to treatment, neither form of legal restraint is associated with any perception of coercion in treatment. Conversely, non-adherent patients considered legal mechanisms of enforced treatment to be more coercive (Elbogen et al. 2003). Interestingly, some diagnoses were not found to be related to adolescents’ adherence (original publication IV). Similarly, six studies identified in the systematic review indicated that diagnoses of severe mental illness were negatively associated with adherence (Original publication II), although another five reported no such effect (Original publication II). Presumably, it is the patient’s mental state and symptoms that influence adherence rather than the diagnosis itself, and it is important to note that mental illnesses which have identical diagnoses can actually vary considerably in terms of severity and symptoms.
The empirical research presented herein also suggested that self-mutilative behavior is predictive of treatment non-adherence in adolescents. However, suicidal thoughts and suicide attempts were not (original publication IV). Shain and the American Academy of Pediatrics Committee on Adolescence (2007) state that suicide among adolescents is a serious problem in the USA, and that adolescent girls are at particular risk of suicide if they are in receipt of psychiatric care, are bullied, or bully others (Luukkonen et al. 2009). Adolescents who had attempted suicide and were suffering from affective or anxiety disorders were less adherent to medication treatment (Burns et al. 2008). On the other hand, suicidal ideation was found to be related to nonadherence to medication among adults (Qurashi et al. 2006). In Finnish adolescents, self-cutting is most prevalent among girls, and risk factors were found to be depressive mood, drug abuse, somatic complaints and poor school performance, as well as poor family relationships (Laukkanen et al. 2009). It has been found that overweight adolescent girls are associated to self-mutilative behavior and low self-esteem, depression or dysfunctional emotion can be possible connective factor between overweight and self-mutilative behavior (Riala et al. 2011). Also, especially self-cutting of adolescent is associated to higher dissociation levels (Tolmunen et al. 2008) and further dissociation has been found to be related to the age of 15 or less, smoking, alcohol or illegal drug use and social isolation (Tolmunen et al. 2007). According to Hintikka et al. (2009) adolescent’s self-mutilative behavior is related to major depressive disorder, alcohol use and internalizing behavior. They also suggests that girls who direct their feelings inward are in a risk of seeking alleviation by self-cutting for their mental symptoms of depression and anxiety. In addition, it has been found that increasing social support for adolescence could reduce the likelihood of non-suicidal self-injury (Christoffersen et al. 2014). However, self-mutilating adolescent wants to be helped by adult, including parent, health care professionals but also teachers (Rissanen et al. 2008, Rissanen et al. 2009). It is an intentional act in where adolescent can be too ashamed or is unable or unwilling to ask for help verbally but is still hoping that someone would help them (Rissanen et al. 2008).

Finally, the literature review suggested a negative correlation between age and adherence in adolescents (original publication II). However, no such correlation was observed in the empirical research (original publication IV). Similarly, age was not associated with treatment drop-out (Gonzales et al. 2011) or appointment attendance (Murphy et al. 2013) in certain previous studies. Although Adeponle et al. (2007) found that nonadherence to outpatient treatment
increased among younger patients. Aside from age and gender, the relationships between the familial and clinical variables that affect adherence were not investigated in this study due to the small sample size considered.

**The definition of adherence**

The definition of adherence developed in this study was largely based on the synthesis developed based on the literature review (original publication I), but was augmented with some points revealed by the empirical research on inpatient adherence. Specifically, more detailed points about cooperation among adolescents and the importance of voluntary participation and desire for treatment were incorporated into the definition of adherence, and criteria relating to unwillingness and unmotivated behavior were added to the definition of nonadherence. As mentioned previously, adherence is an ongoing process and therefore not a steady state in which the patient passively receives treatment (Longhofer & Floersch 2010, McNicholas 2012). In addition, Vuckovich (2010) highlights the role of adherence as a process in which patients participate voluntarily to manage the effects of illness. The definition ultimately developed in this study thus describes the phenomenon of interest well and is more appropriate than other definitions that have been put forward.

Nevertheless, the lines between different concepts associated with adherence are blurred, especially those between “adherence” and “compliance.” Vuckovich (2010) has discussed these concepts in detail, and says that they differ in that adherence is a voluntary behavior based on cooperation between the patient and psychiatric treatment team whereas compliance implies that the patient accepts treatment because they are forced, coerced, persuaded or pressured to do so. A patient is also compliant if they agree to take medication without questioning it. Compliance is thus more likely to occur when dealing with severely mentally ill patients receiving involuntary treatment, and achieving compliance is not sufficient to promote the long-term benefit of persistently mentally ill patients. Instead, the goal must be adherence, in which the patient cooperates actively and willingly chooses to accept treatment.

These arguments are consistent with the results presented in this study: involuntary treatment was strongly linked to nonadherence among adolescent inpatients (original publication IV). These adolescents represented extreme examples of nonadherence. However, the line between compliance and adherence is not always well defined nor has it been studied in detail, so it may be
impossible to state whether a patient is exhibiting adherence or compliance in some cases. Also, researchers are still using both of these terms as well as others that relate to similar phenomena. Also, while both adherence and compliance remain in active use by researchers, there are also a number of less popular terms that are used in discussions of related phenomena. Moreover, one might reasonably ask whether securing adherence (or even compliance) is important when dealing with patients who are severely mentally ill – passive conformity with prescribed treatment may well be in the patient’s best interest under such circumstances.

Sutherland & Harkness (2007) investigated daily life on a pediatric inpatient psychiatric unit housing patients aged from 5 to 18 years. They found that the children were put in groups, followed assigned schedules, and had few opportunities to develop skills of independent decision making. Importantly, the staff of the psychiatric team tried to provide a safe and kind environment where the children were supported and their emotional needs were catered to: for example, staff would tell bedtime stories or offer hugs, and there was a “goodbye book” in the discharge area which contained messages from the staff. It should also be emphasized that adolescents’ inpatient treatment does not just involve personal treatment relationships; patients also participate in therapeutic treatment groups, occupational and music therapy and interact constantly with other adolescents and members of the psychiatric treatment team, all of which contribute to treatment (Marttunen & Kaltiala-Heino 2011). The adolescents examined in this study followed similar routines and had comparable interactions (original publication III, IV). Therefore, could it be possible that the adolescents are “coddled” in the inpatient ward, or that the treatment is too accommodating? If so, this might make the inpatients unwilling to seek recovery and discharge. Alternatively, one might ask at what point an adolescent inpatient should be considered adherent, given that they are separated from their family. Inpatient treatment is provided within the context of a specific treatment organization in a hospital rather than at home; the difference between the two environments may be substantial and have profound effects. When investigating adherence, these thoughts need to be discussed.

However, it must also be emphasized that while most mental health treatment services are community-based (Marttunen & Kaltiala-Heino 2011, Pylkkänen 2013), adolescents with severe mental illnesses or problems must be treated in psychiatric hospitals or special health care facilities (Marttunen & Kaltiala-Heino 2011). It is therefore important to understand factors affecting treatment
adherence among adolescents with psychiatric conditions in both outpatient and inpatient environments. Depending on the severity of their illness, the adolescent will be treated in the community or in a hospital, with the community option being preferred in most cases. Any adolescent admitted to a psychiatric inpatient ward is thus very likely to truly need care, so it is important to ensure their adherence both to promote effective inpatient treatment and to encourage future adherence during post-discharge community-based follow-up treatment. On the other hand, if community-based treatment is initiated at a sufficiently early stage, it may be possible to avoid the need for inpatient treatment in the first place, which would be desirable because community-based psychiatric care is very cost-effective (Pylkkänen 2013).

Overall, the results presented in this study indicate that the concept of adherence is very complex and has several different features and horizons. The definition of adherence is necessarily closely tied to the context in which it is to be investigated or assessed. It is difficult to achieve good and consistent treatment adherence among adolescents with mental illnesses, but adherence can be promoted by the actions of treatment staff (Eisenmann 2012, Gearing et al. 2012b). It is therefore important to ensure that treatment providers understand the importance of adherence in order to ensure that adolescents continue with their prescribed regimes (Gearing et al. 2012) and thereby avoid the worst short- and long-term consequences of mental illness (MacBeth et al. 2013).

6.2 The trustworthiness of the study

This study was conducted using mixed research methods and therefore incorporates both qualitative and quantitative research techniques. An exploratory design was used in which qualitative data were collected first (original publications I, II and III), followed by quantitative data (original publications III and IV) in order to achieve a comprehensive initial exploration of the research phenomenon. The research methods used in the two phases of the study are discussed separately in the following sections because it is important to separately assess the trustworthiness of results based on qualitative data and the validity and reliability of quantitative research (Polit & Beck 2012). The discussion of the study’s trustworthiness is thus divided into three parts, one focusing on the literature review, the second dealing with the qualitative research methods, and the third concerning the quantitative research methods.
6.2.1 Trustworthiness of the systematic literature review

Systematic reviews are reviews that methodically integrate research evidence based on a specific research question using well-developed sampling and data collection procedures which are discussed in advance and clearly laid out (Droogan & Cullum 2010, Polit & Beck 2012). A systematic review may yield very different conclusions to a conventional literature review, particularly concerning the characteristics of evidence presented in previous studies. This is because they are conducted using a process of development and testing according to a detailed protocol involving quality appraisal to ensure that all of the relevant evidence is gathered from studies that have some bearing on the research question of interest (Polit & Beck 2012, Salmond 2012). Integrative systematic reviews involve gathering and integrating data and findings from studies conducted using diverse approaches, including qualitative, quantitative, and mixed methods studies (Flinkman & Salanterä 2007, Polit & Beck 2012). The systematic literature reviews presented in this study were conducted according to established principles (Polit & Beck 2012, The Joanna Briggs Institute 2008). For the sake of convenience, the reviews (i.e. original publication I, II) are henceforth referred to as “systematic literature reviews” even though technically they were both integrative systematic literature reviews.

Specific procedures were followed to avoid publication, language or selection bias and to increase the trustworthiness of the reviews (Salmond 2012). Well defined inclusion and exclusion criteria were used to identify studies relevant to the review. The inclusion criteria stipulated that only peer reviewed studies which answered detailed and specific research questions could be considered.

In addition, the search terms were defined by the author in collaboration with an information specialist from the medical library of the Faculty of Medicine at the University of Oulu. The information specialist also provided assistance with the search of the four databases. The sorting process, whereby the studies identified by the initial database search were assessed with respect to the inclusion and exclusion criteria, was conducted in collaboration with a second researcher and documented step by step to ensure that the process can be repeated by independent workers and to establish trustworthiness (Salmond 2012, The Joanna Briggs Institute 2008). The trustworthiness of the results was further enhanced by having two people involved at each step of the search and quality appraisal process (Polit & Beck 2012).
The JBI-SUMARI package validity checklists (Pearson et al. 2009) were used to critically assess the studies identified in the initial database searches. Before the quality appraisal, researchers discussed the checklists to establish a mutual understanding of their contents. It was decided that studies would not be included in the reviews if their results were not clearly linked to the research questions or the methods used were not clearly described. Quality appraisals were then performed by the two researchers individually, but the researchers periodically compared and further discussed their appraisals to ensure that a mutual understanding of the inclusion criteria was preserved. These actions were taken to ensure the trustworthiness of the subsequent review.

The reviews concentrated on adolescents with mental disorders that have fairly similar mental problems or disorders in order to obtain a comprehensive overview of knowledge concerning treatment adherence within this group, and to identify commonly used definitions of adherence. In addition, information on factors affecting treatment adherence was sought. To avoid the inclusion of irrelevant material, tightly defined inclusion and exclusion criteria were established so as to provide a broad picture of knowledge concerning adolescents’ adherence to medicine and non-pharmacological treatment while giving equal priority to as many different forms of treatment as possible. It should be noted that using broader inclusion criteria would have yielded more complex definitions and results concerning treatment adherence, which would have made it harder to meaningfully answer the research questions targeted in the reviews. As such, the decision to use very tight inclusion criteria represents both a strength and a weakness of this study: while it facilitated the production answers to specific research questions, it may also have caused us to overlook information that would have been of relevance. For example, adolescents often suffer from substance abuse, and some publications on substance abuse may have been omitted from the review process due to the tightness of the inclusion criteria.

In addition, it is possible that our search protocol may have discarded some relevant studies because of the search terms used to query the databases. Papers written in languages other than English were not excluded during the initial searches, although some could not be included in subsequent steps due to language barriers. The searches and the development of the reviews were conducted according to the PRISMA guidelines (Moher et al. 2009). A narrative data analysis approach was used because the gathered data were insufficiently homogenous for statistical pooling and meta-analysis. A narrative approach was
optimal given the objectives of the reviews and the contents of the reviewed studies (Polit & Beck 2012).

### 6.2.2 Trustworthiness of the qualitative research methods

The trustworthiness of qualitative research is evaluated in terms of credibility, dependability, confirmability and transferability. These aspects and the means by which they are demonstrated for original publications I, II and III are discussed below (Lincoln & Guba 1985, Shenton 2004, Thomas & Magilvy 2011).

**Credibility** can be understood as a measure of confidence in the truth of the used data and its interpretation (Shenton 2004, Thomas & Magilvy 2011, Polit & Beck 2012). Of all the data examined in this study, it is the researcher’s handwritten notes based on the case notes for the participating adolescents for which it is most important to demonstrate credibility. Two sets of patient case notes were used: original publication III used data gathered from notes on discharge summaries written by doctors in charge of treating adolescent patients, and original publication IV used data gathered from patient case notes (i.e. documents written by both doctors and other treatment staff) for adolescents treated in the inpatient ward. To assess the credibility of these data sets, it is important to consider the contents of the case notes and the researcher’s ability to accurately extract information relating to the research questions and interpret it correctly. It should be noted that the researcher has clinical experience from working in psychiatric treatment in an adolescent inpatient ward and is therefore familiar with treatment procedures and methods. The researcher therefore understood the case notes and their contents. In order to increase the credibility of the handwritten notes, the researcher collected the data and analyzed it individually (Lincoln & Cuba 1985).

The retrospective chart review or medical record review is generally useful research method that is often used in healthcare investigations to answer specific research questions (Vassar & Holzmann 2013). The primary purpose of medical records is to enable good care, support clinical decision making and clear communication, and ensure continuity of care (Zegers et al. 2011). However, records and charts are also potentially valuable sources of research data, which can be tapped by performing a retrospective chart review (Gearing et al. 2006). However, it is possible that the records may be incomplete or that documentation may be missing, and researchers must be aware of this in order to ensure the trustworthiness of the research (Gearing et al. 2006, Vassar & Holzmann 2013).
In this study, the researcher was aware of this risk and therefore continuously assessed the quality of the information during the data gathering process in order to ensure that it was relevant to the research question (original publication III) or to the classification process (original publication IV). In addition, the data collection process was discussed with other members of the research team and assessed to ensure that the necessary information was received. The team included experts who were familiar with the process of writing hospital notes and interpreting doctors’ discharge summaries. The discharge summaries contained comprehensive information about each adolescent’s inpatient treatment, which was gathered to provide a large body of data for analysis. While this approach may have limited the scope of the investigation, it also strengthened the resulting conclusions because the final discharge reports were not restricted to a specific topic or area. Moreover, it can reasonably be assumed that the information in the reports was recorded accurately and without excessive bias or influence from pre-existing information concerning the research area. They were explored because there were no established instruments or previous studies to draw on in this study. However, the hospital case notes of the treatment staff and doctors included very large amounts of information. While this was not a problem when merely seeking to classify individual adolescents as adherent or non-adherent, it would have been challenging to sift through such large bodies of data to answer a more complex research question such as that considered in original publication III, which is why the more concise discharge summaries were preferred in that case.

**Dependability** concerns the stability or reliability of data over time and under varying conditions (Shenton 2004, Thomas & Magilvy 2011, Polit & Beck 2012). In this study, the hospital case notes including the discharge summaries (original publication III) and case notes (original publication IV) were assessed at the beginning of the data collection process. During the data gathering work for original publication III, the first ten sets of data gathered from the discharge summaries were critically assessed to ensure that relevant information had been extracted. The same procedure was applied during the data gathering process for original publication IV. In both cases, the data collection and analysis processes were as discussed and reflected on with other members of the author’s research team.

**Confirmability** relates to the objectivity and neutrality of the data; it must be considered in cases where the results reflect or represent information provided by participants and the conditions of the inquiry (Shenton 2004, Thomas & Magilvy 2011, Polit & Beck 2012). It should be stressed that in any investigation, the
researcher’s own interpretations of the data and subjective views may influence the analysis. The analytical process used in original publications I, II and III has been reported honestly and in a credible way such that the reader can easily assess the data gathering and analysis process, thereby increasing trustworthiness (Elo et al. 2014). An inductive approach was adopted when dealing with qualitative data (original publications I, III) such that the data gathering and analysis procedures were guided by the research questions to be answered (Elo & Kyngäs 2008). Such analyses can also be described as being data-driven, as was done in publication II (Braun & Clarke 2006). The entire qualitative data analysis process has been discussed using the theme names (original publication II) and categories (original publication III) used in the published papers in order to increase the trustworthiness of the results and the ease of comparing the raw data to the published conclusions (Elo et al. 2014). However, the fact that only one researcher conducted the data analysis process may reduce the trustworthiness of the qualitative research.

Transferability concerns the extent to which results of the data can be transferred to other similar settings or groups. It is essential for researchers to provide sufficient descriptive data for a reader to evaluate the applicability of the data to other contexts or settings (Shenton 2004, Thomas & Magilvy 2011, Polit & Beck 2014). This point was noted in the original publications (I, II, and III). However, issues of transferability were not especially pressing in this study because the investigated inpatient treatments were conducted between the years of 2001-2006. It is possible that inpatient treatment practices had been changed and refined between the writing of the case notes and the performance of the analysis. However, as noted in the results section, the inpatient treatment practices were broadly similar to those used at the time of writing (Marttunen & Kaltiala-Heino 2011). Therefore, the results should be relevant to similar settings or groups. However, it should be noted that the transferability of the conclusions could have been increased by collecting data from other hospital districts in Finland so as to obtain a more comprehensive overview based on a larger and more varied sample. On the other hand, this would have presented complications associated with comparing case notes prepared according to different writing guidelines and with different contents. In addition, the treatment methods used in the different hospital districts may have differed. Consequently, it would have been difficult to assess adherence in a consistent way across all participating hospitals.

On the other hand, the systematic review increased the transferability of the results because it included data from international studies exploring adherence to
medication and non-pharmacological treatment among adolescents. As described previously, the systematic review established the conceptual framework and foundations for the empirical research, and the classification system used to determine adherence was developed from the synthesis of literature definitions of adherence. It was decided to synthesise a definition of adherence rather than creating one by means of concept analysis. To this end, the systematic literature reviews were conducted to search the essential and substantive literature and establish a basis for concept synthesis in order to identify, name and describe the changeable concept (Grove et al. 2013) Concept synthesis is data-based process that involves labelling and linking the concept to form propositions (Meleis 1991). In contrast, concept analysis is a strategy that identifies a set of characteristics associated with the meaning of a concept to serve as a platform for theory development (Polit & Beck 2012, Grove et al. 2013). In this study, concept synthesis was considered more appropriate because the existing definitions of adherence exhibit similar characteristics. The synthesized definition of adherence developed during the systematic review process (original publications I, II) and then refined after further analysis and empirical research (original publication IV) should be useful in future studies and also in the practical treatment of adolescent inpatients.

6.2.3 Validity and reliability of the quantitative research methods

Validity is a criterion of quality relating to the accuracy of inferences made in a study and the extent to which they are well founded. To assess validity, research reports are critically appraised to determine their scientific soundness and the consistency of the reported results (Polit & Beck 2012, Grove et al. 2013).

Internal validity refers to the extent to which items in an instrument adequately represent the content of the concept being measured, but also it reflects the ability of the used concepts to cover the studied phenomenon (Polit & Beck 2012). In this study, no instruments were used and majority of the variables were transferred from the STUDY-70 project data, including the background variables (age, gender), specific clinical variables (n=19) and family variables (n=20). Information on these variables was extracted by means of interviews conducted according to the semi-structured Schedule for Affective Disorder and Schizophrenia for School-Aaged Children, Present and Lifetime (K-SADS-PL) (Kaufman et al. 1997). The interviews were conducted by either the treating physician or a trained medical student under the supervision of the treating
physician. The data gathered via the K-SADS-PL integrates information given by the adolescent, the physician’s evaluation, and, in some cases, information obtained from interviews with the parents. Parents were only interviewed if data from the adolescent interview were missing or considered unreliable. A full description of the instrument is available at http://www.psychiatry.pitt.edu/research/tools-research/ksads-pl (online 01.11.2013).

The European Addiction Severity Index (EuropASI) interview is a protocol for face-to-face structured interviews was used to assess familial and clinical factors (Kokkevi & Hartgers 1995). These interviews were performed by the staff nurse. The instrument contains questions on multiple life domains and related problems: physical health, employment, financial support, criminal behaviour, family and social relations, psychiatric symptoms, and alcohol and substance use (Kokkevi & Hartgers, 1995). The STUDY-70 project used single items from the EuropASI instrument to gather qualitative information about the subjects and their socio-demographic background. In addition, information on the family variable, i.e. the Global Assessment of Relational Functioning (GARF) was transferred from STUDY-70 project data. GARF scores were determined for adolescents and their families by a multi-professional psychiatric team. The information on the inpatient adolescents’ familial and clinical details can thus be considered reliable because they were obtained by trained professionals. No individual or subjective information on symptoms from the K-SADS-PL or EuropASI interviews or GARF evaluations was included in the analyses.

When assessing validity of this study, the used methods of STUDY-70 need to be considered. As mentioned, this study includes data gathered during interviews (K-SADS-PL and EuropASI) as well as assessments of GARF. Semi-structured interviews such as K-SADS-PL are known to be valuable tools for obtaining accurate and objective DSM-III-R and DSM-IV-based diagnoses in adolescent psychiatry (Ambrosini 2000, Kaufman et al. 1997, Kim et al. 2004). K-SADS-PL assesses past and present episodes of psychiatric disorders. Its retest-reliability is rated good to excellent (.77 to 1.00), and its concurrent validity and inter-rater agreement are both high (93% to 100%) (Kaufman et al., 1997, Ambrosini, 2000). In addition, EuropASI interviews are also powerful and useful methods for assessing adolescents (Lopez-Goni et al. 2012); Scheurich et al. (2000) report moderate to good internal consistency (.69 to .92) for composite scores and moderate to excellent interrater reliability (intraclass correlation: .62 to .99) for data gathered in this way. According to Denton et al. (2010) and Stein
et al. (2009) the assessment of family relational functioning (GARF) has been found to be a valid tool in clinical settings.

In this study, variables relating to involuntary treatment and treatment duration were also included in the statistical analyses. Information on these variables was collected from original publication III and was based on the content analysis conducted during the qualitative phase of the study (Elo & Kyngäs 2008). Quantification was achieved by assigning each adolescent in the sample to a category with respect to each variable and counting the number of items in each category. In quantification, variability is expressed numerically in terms of the relative prevalence of a given attribute (Polit & Beck 2012). By doing this, it was possible to receive information about the most general or common characteristics describing inpatient adherence to the treatment. However, it has to be pointed out that these factors could also mean that some relevant information may have been omitted or overlooked in the analyses. This could indicate that the reports do not include every detail of the treatment process. Also, there is an increased risk of missing chart documentation for adolescents who have been mentally ill for a long time (Cradock et al. 2001).

Further, adolescents were classified as being adherent / nonadherent to medicine and non-pharmacological treatment (original publication IV). The classification table used was based on systematic review and the concept synthesis to receive exact definitions of adherence, but the results and conclusions of the original publication III were added to the definition in order to ensure that it would correctly capture each inpatient’s treatment adherence.

External validity reflects the degree of generalizability of the results obtained in a study (Polit & Beck 2012). The studies presented herein have limited external validity because they examined a fairly small sample and focused on a single organization providing psychiatric inpatient care. The findings therefore cannot be generalized. However, they still provide valid information about inpatient adolescents’ adherence to medicinal and non-pharmacological treatment, which could be used in the treatment of the psychiatric inpatient adolescents. The population examined in this study represents an epidemiologically unselected sample of adolescents in need of inpatient psychiatric hospitalization in Northern Finland.

Reliability represents the degree of consistency in the methods of measurement used (Polit & Beck 2012, Grove et al. 2013). Due to the small sample size used in this study, statistical significance testing was performed using Fisher’s exact test, which is a superior alternative to Pearson’s $\chi^2$ test for 2x2
tables when dealing with small samples (Munro 1997, Forthofer et al. 2007). A stepwise binary logistic regression analysis was used to identify significant predictors of non-adherence. Variables were selected for inclusion in the logistic model on the basis of Fisher’s exact test, and assembled into a logistic regression model using stepwise selection according to the Forward LR method (original publication IV). The regression analysis yielded the following Nagelkerke values for each treatment group: partial adherence 0.237; medication adherence 0.214; non-pharmacological treatment adherence 0.358; and all referred treatment 0.390. The corresponding -2 Log likelihood values were as follows: partial adherence 61.844; medication adherence 65.457; non-pharmacological treatment adherence, 74.169 and all referred treatment 75.527. These values represent reasonable levels of reliability (Munro 1997, Forthofer et al. 2007). More reliability data can be found in original publication IV.

6.3 Summary of strengths and limitations

An systematic literature review (original publication I, II) was conducted in this study due to the scattered and fragmented distribution of information on adolescents’ adherence to treatment in mental health and psychiatric settings across the primary literature. The systematic reviews provided information about adolescent outpatients and inpatients’ adherence to treatment. However, there were more studies on outpatient treatment than inpatient treatment, so it should be assumed that the results in the reviews are biased towards outpatient treatment. In addition, the reviews provided the framework and conceptual basis for the empirical studies. This can be considered to be a strength of the study because it means that the empirical investigations were rooted in a comprehensive and detailed understanding of the studied phenomenon. However, the systematic literature review can also be considered limiting because there was a lack of more comprehensive empirical research and evidence. The search process for the systematic literature review was conducted by two researchers using very tight inclusion / exclusion criteria and a quality appraisal protocol. All of these actions can be considered to strengthen the systematic review and this study. However, it is possible that some relevant papers would have been excluded by the stringency of the inclusion criteria.

The empirical data of this study were collected from hospital case notes and discharge summaries written by a doctor in charge of adolescents’ treatment (original publication III) and treatment notes written by doctors and treatment
staff (original publication IV). It must be noted that hospital case notes were not written to support this study (or any other research), so it can be assumed that they describe the adolescents’ conditions and treatment in an honest and objective way. It is reasonable to assume that these data represent the totality of the information on the adolescents’ treatment, and that the doctor in charge would be the member of the psychiatric treatment team who is best positioned to accurately describe the treatment regime. However, there is inevitably some relevant information that is not included in case notes, which may affect the validity of this study. Some alternative data gathering methods were considered; for example, questionnaires could have been sent out to adolescents or their parents to assess treatment adherence. However, adherence to mental health treatments is both sensitive and difficult to assess, so it is perhaps likely that the response rate to the questionnaires would have been low, and the answers may have been misleading about the true rate of adherence.

It has to be pointed out that one limitation of this study’s second phase (original publication III, IV) is that most of the family and clinical variables were collected at the start of each adolescent’s stay in Unit 70, after which they were transferred to some other ward in the hospital. Therefore, the data gathered for some clinical variables such as the patients’ diagnoses may not have accurately reflected the patient’s state later on in the treatment process; it is possible that different results would have been obtained if data had been collected at a later point in the treatment process. However, this issue is not hugely relevant for most of the clinical or family variables, so the results can be considered reliable for the most part. In addition, due to small sample size, the relationships between the variables were not investigated. Such an analysis would however have provided important information.

As discussed earlier on in this section, the results presented herein should not be generalized to all adolescents with mental health problems or all adolescents in specialized psychiatric treatment. The sample size of this study was fairly small. However it does describe inpatient adolescents’ adherence to both medication and non-pharmacological treatments, and therefore provides potentially valuable insights for psychiatric team members providing inpatient treatment to adolescents. The sample size of this study could have been increased to cover other psychiatric hospitals in Finland that provide inpatient treatment for adolescents. However, treatment methods and guidelines for writing patient case notes may differ between hospitals, and such variation would have reduced the study’s validity. In addition, the criteria for hospital admissions may have varied,
especially when comparing hospitals in Southern and Northern Finland. In northern regions, the long distances between settlements may have influenced admissions, and the number of beds in relation to the size of the adolescent population would be smaller than it is in the south. In addition, it is not likely that detailed information on family and clinical factors such as that gathered during the STUDY-70 project would be available in other hospitals.
7 Conclusions

7.1 Main conclusions to be drawn from the study

The main conclusions of the studies presented in this study are:
1. Literature definitions of adherence vary appreciably, and depend on the context examined.
2. Treatment adherence is an ongoing process, but it can be achieved and should be regarded as a key treatment goal.
3. Treatment adherence among adolescents is related to willing cooperation and a desire for treatment to relieve mental symptoms. Family relationships and functionality also have important effects.
4. Adolescent’s mental symptoms, especially self mutilative behavior can be linked to treatment nonadherence. Under certain very specific circumstances, adolescents may be compelled to undergo involuntary treatment. However, there was a strong link between involuntary treatment and nonadherence.
5. Cooperation and a desire for effective treatment promote both inpatient and outpatient adherence, as do strong positive familial functioning. This is true for both medication and non-pharmacological treatments.
6. Adolescents who have received special services at school are more likely to adhere to inpatient treatment regimes.
7. Adherence to treatment affects treatment outcomes, which must be taken into account in order to achieve effective and high-quality treatment of adolescents.

7.2 Suggestions for future research

In the future, it would be essential to assess and investigate inpatient adherence to medication and non-pharmacological treatment with a larger sample size. Such a study would provide important insights into treatment adherence among adolescents in a larger context. Because there have been few studies on inpatients that examine adherence to both medication and non-pharmacological treatments, it would be important to begin such a study by gathering information from as many sources as possible. In addition, it would be useful to gather data from other countries to enable international comparisons and provide a truly comprehensive picture of factors affecting treatment adherence among adolescent inpatients.
It will also be important to investigate inpatient adolescents’ adherence to treatment based on adolescents’ own views of adherence. This will require the development of valid experimental methods and well-defined ways of measuring adherence. The development of such methods would provide further opportunities to explore the meaning and definition of adherence, and to distinguish between adherence and compliance. Such an investigation would also provide a solid foundation for more general studies on adherence. Another aspect that merits further study is the influence of familial factors on treatment adherence among adolescents. In particular, it would be useful to understand how parents’ status and behavior affects adherence. Is an adolescent more likely to be nonadherent if one of their parents opposes the treatment? This study demonstrated that medication treatment adherence rates were greater than those for non-pharmacological treatment among inpatient adolescents. It would be useful to know why this is so.

Finally, several potential promoters of adherence have been identified in the literature. These should be investigated among adolescents in psychiatric care to better understand how individual promoters influence adherence. In particular, patient education has been found to have positive effects on adherence. Literature data indicate that the period immediately after discharge from psychiatric care is associated with high rates of nonadherence. It would therefore be interesting to see how different promoters influence maintenance of adherence during this period, and to monitor their effects on readmission to inpatient facilities.

7.3 Implications of the study

This study deals with several core elements of nursing science: adolescent, treating illnesses with the aim of relieving symptoms, inpatient treatment, and the effects of the environment on adolescents. Systematic reviews were conducted to compile and analyze existing knowledge and empirical investigations were designed to build on this knowledge by exploring adherence to medication and non-pharmacological treatments among adolescent inpatients at a psychiatric hospital, which has not been studied in detail before. The results of this study provided insights relevant to both outpatient and inpatient treatment, and represent new and well-validated information that can be used in practice by members of psychiatric treatment teams. While the results should not be carelessly generalized, they constitute a good foundation for more extensive qualitative investigations into adherence among adolescent inpatients. Psychiatric
treatment teams can use information from this study to improve their understanding of adherence among adolescents and thereby design treatment programs and interventions in a way that will maximize the likelihood of long-term adherence by promoting positive attitudes to treatment in the adolescent, their family, and society in general.

The results also have broader social implications, suggesting that it is important for nonadherence adolescents to be identified at an early stage so that interventions can be conducted to avoid the risk of readmission or missed outpatient appointments. This would be desirable in terms of both public health and cost effectiveness.

The results of this study could also be used in the training of nurses and specialists in mental health care or psychiatry to highlight the importance of considering adherence from the outset when designing and implementing treatment programs for adolescents.
References


Laukkanen M, Hakko H, Räsänen P & Riala K (2013) Does the use of health care and special school services, prior to admission for psychiatric inpatient treatment, differ between adolescents housed by child welfare services and those living with their biological parent(s)? Community Ment Health J 49(5): 528-539.


## Appendix

Table 3. Family variables considered in preliminary bivariate analyses and final logistic regression models.

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*Variables were included Logistic regression analysis
Table 4. Clinical variables considered in preliminary bivariate analyses and final logistic regression models.

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*Variables were included Logistic regression analysis*
Original publications


II  Timlin U, Hakko H, Heino R & Kyngäs H. Factors relating to adolescent adherence to mental healthcare treatment – A systematic integrative review of the literature. (manuscript)


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Original publications are not included in the electronic version of the dissertation.
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ADOLESCENT'S ADHERENCE TO TREATMENT IN PSYCHIATRIC CARE

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UNIVERSITY OF OULU
FACULTY OF MEDICINE
MEDICAL RESEARCH CENTER OULU
OULU UNIVERSITY HOSPITAL
HELSINKI UNIVERSITY CENTRAL HOSPITAL
DEPARTMENT OF ADOLESCENT PSYCHIATRY