

**Outcomes of preadolescent children after inpatient
psychiatric admission:
A scoping review and qualitative study**

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requirements for the degree of MSc (Med) Psychiatry

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Declaration

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Dedication

I dedicate this thesis to the University of Cape Town, where many years ago I was excited to discover that knowledge *could* be questioned; and to the memory of my father Advocate Harry Swart, who lectured in the UCT Faculty of Law. He would certainly have celebrated this achievement at his favourite Indian Restaurant.

Abstract

Background: Approximately twenty percent (20%) of children and adolescents have mental health disorders and between 50–75% of all adult mental illness has its onset before the age of 18. Few under 18-year-olds with mental health disorders are, however, admitted for psychiatric inpatient care. The majority of those are adolescents who present with emerging serious mental health disorders. Very little is known about inpatient admission of preadolescent children (under 13 years) with mental health disorders. A review in 2000 showed mixed results about outcomes from admissions and highlighted a number of challenges with outcome studies.

Objectives: The purpose of this study was to investigate the outcomes of preadolescents (hereafter referred to as ‘children’) after inpatient admission, both locally and internationally.

Methods: To meet the first aim, we performed a scoping review. Two reviewers independently searched EBSCOhost and Scopus (January 2000 – February 2017), using keywords ‘inpatient’; ‘psychiatry’; ‘psychiatric unit’; ‘mental health’; ‘children’; ‘treatment outcome/s’; ‘follow-up’; ‘secondary care’; to identify studies examining child (0–12 years) psychiatric inpatient outcomes. To meet the second aim, perspectives of convenience sampled parent-child dyads, who were previously patients at an inpatient psychiatric unit for under 13-year-olds in Cape Town, South Africa, were gathered using in-depth individual interviews. Data generated from the interviews were transcribed and analysed using thematic analysis.

Results: Seventeen studies were identified by the PRISMA-guided search strategy in the scoping review. Measurements used differed widely. Significant improvements were reported at discharge and was maintained in short-term follow-up (1–4 months) studies. However, medium-term (5–11 months) and long-term (1 year or more) follow-up studies showed mixed results, with marked deterioration in very long-term studies.

The qualitative study showed that most families found inpatient admission helpful, and indicated positive outcomes, but with ongoing difficulties over time. Two main themes related to outcomes emerged from the 10 parent-child dyads included in the study. The first theme (*“A turn in the road”*) highlighted inpatient admission as the catalyst of positive outcomes. Diagnostic certainty; newly acquired cognitive and behavioural skills; improved parent-child relationships; appropriate school placements; development of peer relationships; as well as follow-up psychiatric care and medication, were seen as contributing to positive outcomes. Conversely, the second theme (*“Still a rough journey”*) described ongoing difficulties including lingering problems despite improvement; minimal improvement when lacking a diagnosis; regression with transition to mainstream secondary school; and negative outcomes associated with lack of peer relationships and discontinuation of psychiatric care and medication.

Conclusion: Taking together findings from our work, inpatient stay for child psychiatric patients was found to result in substantial short-term improvement. Medium-term outcomes were less clear, while long-term outcomes appeared mixed, with potential deterioration in the very long-term. However, the relatively few and diverse studies found in the scoping review made interpretation of the findings difficult. One striking finding from the research, was the absence of internationally agreed outcome measures to inform such research. In this study, qualitative data from families and children who had received inpatient treatment provided several functional outcomes that may be important, both for outcomes research and for post-discharge clinical practice.

Key Words: child, preadolescent, psychiatric, inpatient, outcomes research, South Africa

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Abbreviations

CAMH Child and Adolescent Mental Health

CINAHL Cumulative Index to Nursing and Allied Health Literature

HICs High-income countries

LMICs Low-and middle-income countries

Key Terms

Aftercare /Follow-up care (treatment after psychiatric inpatient discharge)

Child & adolescent mental health

High-income countries

Long-term outcome (1 year or more after psychiatric inpatient discharge)

Low-and middle-income countries

Medium-term outcome (5–11 months after psychiatric inpatient discharge)

Parent /Caregiver perceptions

Psychiatric inpatient admission

Short-term outcome (1–4 months after psychiatric inpatient discharge)

Chapter 1

Background to child mental health and inpatient psychiatry

1.1 Child & adolescent mental health

In children under the age of 18, mental health problems represent the greatest burden of disease (Gore et al., 2011) and 50–75% of all adult mental health problems have an onset before the age of 18 (Jones, 2013). The frequent persistence of mental disorders into adulthood poses a significant challenge to public health (Flisher et al., 2012). Despite these facts, all over the world there are little data available on Child and Adolescent Mental Health (CAMH) services and outcomes, largely because research in CAMH is so limited (Kieling et al., 2011; Pedrini et al., 2012; World Health Organization, 2005). Most research on CAMH comes from high-income countries (HICs) (V. Patel, C. Kieling, P. K. Maulik, & G. Divan, 2013), even though most of the world's children live in low- and middle-income countries (LMICs) (Kieling et al., 2011).

1.2 Child & adolescent inpatient psychiatry

Child and Adolescent Psychiatry emerged as a speciality in the early 20th century. The exact date for the 'foundation' of the speciality is not clear, but Leo Kanner, based at Johns Hopkins University in the USA, is often credited with writing the first textbook of child and adolescent psychiatry (Kanner, 1935). Most scientific discoveries and research in CAMH emerged after World War II, with strong programmes in the United States of America (USA) led by people like Donald Cohen (Yale), and in the United Kingdom (UK) led by people like Michael Rutter (Institute of Psychiatry, London). The beginning of the twentieth century also saw the emergence of residential establishments in the USA and UK for children with mental health problems (Parry-Jones, 1998). These institutions were not necessarily medical facilities, but developed a relationship with the new field of child & adolescent psychiatry (Parry-Jones, 1998). Epstein (2004) commented on the significant advances in child psychopharmacology, cognitive behavioural psychotherapy, and family therapy during the second half of the 20th century. Classical analytical psychotherapy (previously the predominant treatment

modality) was therefore no longer the main influence in residential care environments. Inpatient care began to be seen within the context of outpatient and community care, and the length of institutional stays decreased remarkably (Epstein, 2004). Furthermore, the increasing economic costs made short-term care more attractive (Hersov, 1994). Studies concerning their effect began to focus on outcomes, as opposed to narratives of care (Epstein, 2004).

By the end of the 20th century, child & adolescent psychiatry and mental health had become predominantly an outpatient-based speciality, and the vast majority of children and families are seen for outpatient consultation and treatment. Around the globe a very small proportion of young people with mental health disorders are admitted to inpatient units. The majority of those who are admitted are adolescents, who typically require admission for diagnosis and treatment of serious mental disorders such as severe depression, anxiety, or psychosis. There is therefore a reasonable amount of scientific literature on outcomes of adolescents who require mental health inpatient admissions (Hayes, Simmons, Simons, & Hopwood, 2018). In contrast, there are very limited inpatient units for preadolescents (hereafter referred to as 'children') around the globe (World Health Organization, 2005). As a result, there are also very limited research data available about outcomes after admission to inpatient units for children with mental health disorders.

Admission of a child under the age of 13 who has mental health problems may bring benefits in terms of diagnoses, treatment and 'whole-system' formulations of needs of the child in the context of their family, school system and community. However, inpatient admission may also come with risks, both to the child and family system, as well as to the health system. It may, for example, be traumatising for children to be separated from their families, friends, and educational settings. For families it may lead to feeling disempowered in their own ability to support their child at home. At a systems level, inpatient admission may risk 'abdicating responsibility' from one unit/sector of care (such as clinics, schools, and community organisations) to the inpatient unit, typically run by Departments of Health. For the health system itself, inpatient units are very expensive in terms of physical infrastructure, staffing, are difficult in terms of clinical governance, and has an unclear cost-benefit analysis. In terms of clinical care, there are very limited international data about the outcomes (short, medium, and long-term) of children who had been admitted to inpatient units.

There are therefore many unanswered questions regarding outcomes of children after inpatient mental health admission that could help inform clinical as well as systems conversations about the role and risk-benefit analysis of inpatient units for children with mental health problems.

1.3 Purpose of the study

This study was set up to examine the outcomes of children after inpatient mental health admission, both locally and internationally, through two related aims.

Study aims

Aim 1

To describe the international landscape of research on outcomes (short, medium, and long-term) and follow-up of child psychiatric admissions.

Aim 2

To describe the short, medium, and long-term outcomes of children after discharge from a mental health inpatient unit in Cape Town, South Africa, from the perspectives of the children and their families.

1.4 Overall study design

The study employed a sequential exploratory design with two phases, to meet the two main aims of the project.

Phase 1 (*Aim 1*): A scoping review of existing global peer-reviewed literature on outcomes of children after discharge from inpatient psychiatric admission.

Phase 2 (*Aim 2*): A qualitative study to explore parental and child perspectives of outcomes and determinants of outcomes following child inpatient psychiatric admission.

1.5 Potential significance and impact of the study

To our knowledge, this was the first scoping review of child mental health outcomes after inpatient admission since 2000. An up-to-date review of the research landscape should therefore present a valuable summary to the child mental health community. The qualitative study of parental and child perceptions about outcomes after inpatient admission is, to our knowledge, the first ever study to do so. We therefore hope that these findings may inform not only clinical practice and research in South Africa (where the study is based) and in other low- and middle-income countries (LMICs) but may also contribute to the international literature on mental health outcomes research.

Chapter 2

What happens to children admitted to inpatient psychiatric units after discharge? A scoping review of outcomes

2.1 Background

In children under the age of 18, mental health problems represent the greatest burden of disease (Gore et al., 2011; Jones, 2013) and 50–80% of all adult mental health problems have an onset before the age of 18 (Jones, 2013). The frequent persistence of mental disorders into adulthood poses a large threat to public health (Flisher et al., 2012). Despite these facts, all over the world there are little data available on Child and Adolescent Mental Health (CAMH) services and outcomes, in largely because research in CAMH is so limited (Kieling et al., 2011; Pedrini et al., 2012; World Health Organization, 2005). Most research on CAMH comes from high-income countries (HICs) (Vikram Patel et al., 2013), even though most of the world's children live in low- and middle-income countries (LMICs) (Kieling et al., 2011).

Child and adolescent psychiatric inpatient units are specialised areas of care for severe and/or complex child mental health problems. There is limited access to inpatient units around the world, particularly for preadolescents (World Health Organization, 2005). In addition, relatively little is known about outcomes after admission to mental health units for preadolescents, referred to here as 'children'.

Overall, knowledge of outcomes after child psychiatric inpatient admission remains limited. Four historical reviews examined inpatient treatment for children and its efficacy: (Blanz & Schmidt, 2000; Blotcky, Dimperio, & Gossett, 1984; Epstein, 2004; Pfeiffer & Strzelecki, 1990). Blotcky and colleagues (1984) identified 24 studies between 1936–1982 that involved children. Although all patients showed some improvement, over half were found to have good long-term outcomes if they had not been psychotic, neurologically impaired, or below average intelligence. Aftercare was important, while antisocial behaviour and profound personality disorder had a poor prognosis. However, the authors commented that most of these studies were

conducted without rigorous scientific methods. Pfeiffer and Strzelecki (1990) reviewed 34 child and adolescent studies between 1975–1990, 23 of which studied outcome beyond inpatient discharge. Combining the results of child and adolescent studies and including residential treatment, Pfeiffer and Strzelecki (1990) reported psychiatric hospitalisation, its specialised interventions and aftercare, to be associated with favourable outcomes. Psychosis, neurological impairment, antisocial behaviour, and aggression responded less well. Unlike Blotcky and colleagues (1984), studies that included patients with autism, pervasive developmental disorder, or mental retardation, were not included. However, the majority of studies had unidentifiable methodologies and outcome measures. Outcome criteria were not specified and durations of follow-up were not distinguishable in the results (Pfeiffer & Strzelecki, 1990). In a subsequent analysis, Blanz and Schmidt (2000) reviewed 5 additional studies, two of which concerned post-inpatient outcome of children: Kolko (1992) randomly assigned children to either 2, 4 or 6 months follow-up, and found that at all three intervals the majority had significantly improved. The second study included a number of papers by Sourander and colleagues (Sourander et al., 1995; Sourander, Helenius, Leijala, et al., 1996; Sourander, Helenius, & Piha, 1996; Sourander, Hukkanen, & Piha, 1997; Sourander, Leijala, et al., 1996; Sourander & Piha, 1998). Follow-up was at 5 months, 1 year, and 3 years after inpatient discharge. Despite significant improvement for most, 65% were functioning below average at 5 months and approximately 50% at 3 years. A further paper pertaining to the study was identified in this review. It differed from the previous papers by incorporating all three timepoints, as well as excluding patients that went on to have long-term treatment. Blanz and Schmidt (2000) cautioned that the terms inpatient treatment, inpatient care, and residential care, have been used synonymously for medical and social welfare facilities. They distinguished psychiatric inpatient treatment to be that found in a psychiatric hospital.

Epstein (2004) reviewed 26 inpatient child and adolescent studies (1964–1996). The studies that included children are all captured by the three previous reviews, except for two (Flomenhaft & Sullivan, 1992; Winsberg, Bialer, Kupietz, Botti, & Balka, 1980). Winsberg and colleagues (1980) set out to compare home and hospital treatment of children. The study was abandoned, however, the home group improved significantly after 6 months. Follow-up at 18 months to 3 years found 46% of the hospital group

institutionalised, compared to 28% of the community treated group. Flomenhaft and Sullivan (1992) examined outcomes of children 18 months after they were transferred from acute to long-term hospital care. Half had returned to their families, a quarter went to group residences, and 25% remained inpatients. Diagnosis and psychopathology were found unrelated to outcome.

Dhansay (2012) found 5 prospective child studies, two of which were obtained in this review (Gavidia-Payne, Littlefield, Hallgren, Jenkins, & Coventry, 2003; Mayes, Calhoun, Krecko, Vesell, & Hu, 2001). The other three (Ney, Adam, Hanton, & Brindad, 1988; Oliver & Knight, 1984; Sheerin, Maguire, & Robinson, 1999), found that inpatient admission resulted in significant, sustained improvement; as did another study (Dalton, Daruna, & Bolding, 1991) outside previous reviews, referenced by Imrie and Green (1998). It reported that a statistically significant number of the children had improved a year after hospitalisation. Diagnostic and demographic variables were weak predictors of outcome. Dhansay (2012) remarked that all studies had methodological limitations, and that the unique nature of each psychiatric unit made inferences of outcome data between them difficult.

The key reviews in this area of study as outlined above, suggests that it is not clear what might be ideal outcome measures, or how psychiatric units have defined outcomes, nor how long children have been followed up. Knowledge of the outcomes and quality of care and interventions is needed (a) to ensure a high quality of care, (b) to ensure interventions are evidence-based, (c) to generate evidence for interventions where it does not exist, and (d) to provide data for health economic and policy development purposes.

This study aimed to examine the short, medium, and long-term outcomes of children after discharge from inpatient psychiatric admission, based on existing literature from the year 2000 to address the gap in knowledge.

2.2 Methods

2.2.1 Study design

A scoping review methodological framework was followed (Arksey & O'Malley, 2005). This incorporated identifying the research question, then searching for, identifying, and subsequently selecting relevant studies. The obtained data were then charted and

collated, followed by summarising and reporting the results. The scoping review objective, inclusion and exclusion criteria, and study method, were specified in advance. Inclusion criteria were (i) the study had to be published between 2000–2017; (ii) the study had to be a primary data paper not a review; (iii) the study had to be available in full text; (iv) the study had to examine children with an average age not older than 12 years as part of the sample; (v) the study had to use children followed-up post discharge from an inpatient psychiatric unit, as part of the sample; (vi) the study had to use children that had been inpatients in a psychiatric unit/ward of a hospital, not a home/residential care facility; and (vii) the resulting article had to have been peer-reviewed. As this was a scoping review, no articles were excluded based on methodological quality.

2.2.2 Search strategy

To determine the outcomes of children after discharge from inpatient psychiatric admission, a literature search to identify follow-up studies of child psychiatric inpatients was conducted from January 2000 until February 2017. Since the previous review of this subject was published in 2000 (Blanz & Schmidt, 2000), this scoping review aimed to identify all subsequently published studies to date. Online databases EBSCOhost (Academic Search Premier, CINHAL, Health Source: Nursing/Academic Edition, Medline, PsycInfo, PsycArticles, African Wide Information) and Scopus were searched with no language restrictions, for any study between January 2000 and February 2017 that involved follow-up of child psychiatric inpatients. The databases were searched using the following keywords: 'inpatient', 'psychiatry', 'psychiatric unit', 'mental health', 'child/ren', 'treatment outcome/s', 'follow-up', 'secondary care'. Titles and abstracts were examined using the inclusion and exclusion criteria, after which full articles were retrieved.

As shown in Figure 2.1, the initial Preferred Reporting of Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher, Liberati, Tetzlaff, & Altman, 2009) guided online search, produced 1,590 articles. Twenty-four of these were in German (six with full text English translation). Single articles were found in the following languages: French, Polish, Turkish, Icelandic, Chinese and Japanese. The remaining articles were in English. No article was initially excluded based on language. All articles had

English abstracts. Titles and abstracts were screened, and 235 articles were identified as potentially eligible. Duplicates were removed, reducing the sample to 221 articles. From these, 174 articles were excluded, and the remaining 47 full texts were reviewed to confirm the study inclusion criteria of child age, and follow-up, and inpatient psychiatric unit, producing a total of 17 articles. After screening the English abstracts of nine German articles, one met all three inclusion criteria. Eight did not specify the ages of the participants, and the follow-up period was also unclear in three of the articles. It could be inferred that four of these articles were unlikely to meet the inclusion criteria. All were unavailable in English and were therefore excluded. From the abstracts of the other six articles not in English, none were found to meet all the inclusion criteria.

Two independent reviewers assessed the articles for eligibility (TS, ELD). Disagreements were resolved by consensus between the reviewers and in the case of a dispute, the senior author (PJdV) made the final decision. Figure 2.1 outlines the process involved in the scoping review and final selection of articles. The final sample consisted of 17 articles included in the review.

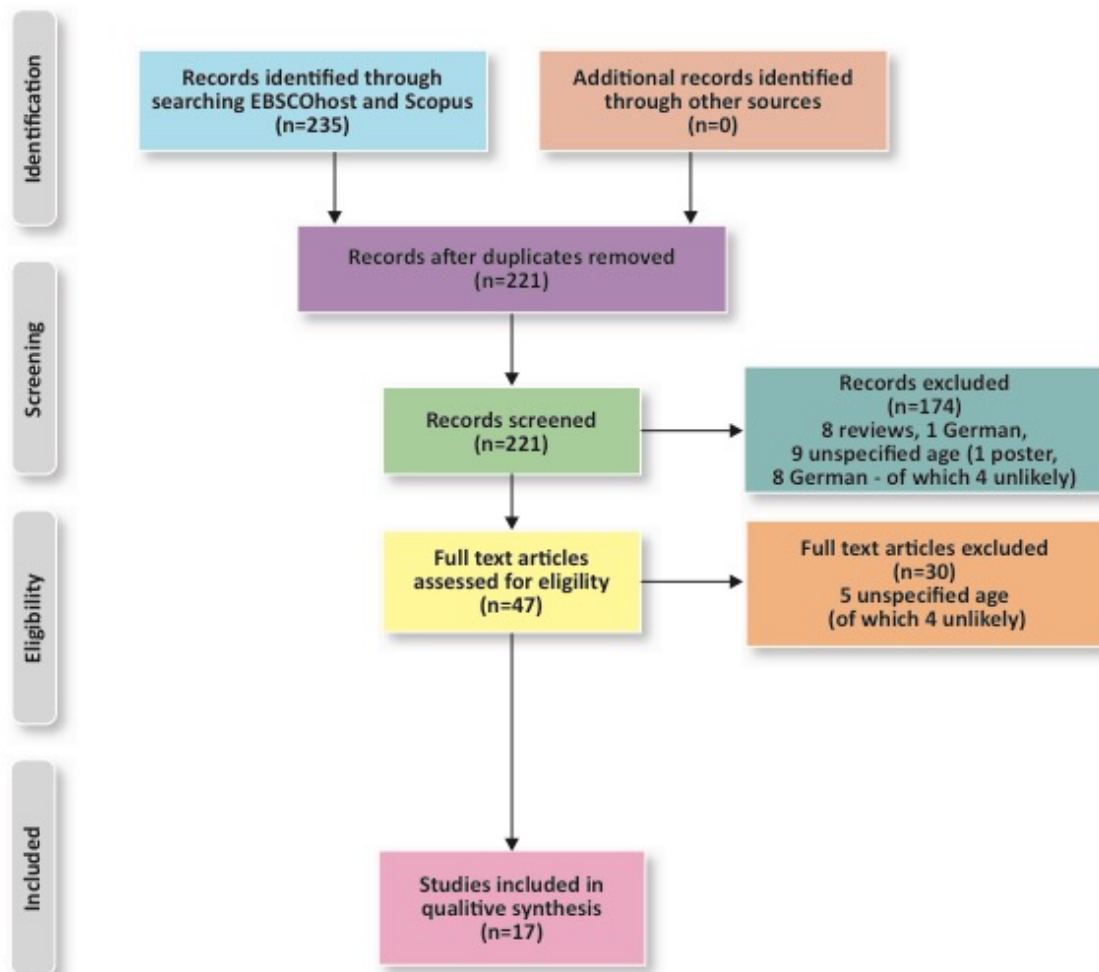


Figure 2.1 PRISMA flow diagram of studies screened, included and excluded in scoping review

2.2.3 Data extraction and analysis

Full text versions of all included articles were collated by the first author and analysed by the first and second author to extract relevant information for the review. The data were analysed by way of a narrative synthesis, as outlined by Popay and colleagues (2006). This entailed three stages: (1) formulating a preliminary synthesis of the selected studies' findings, (2) exploring relationships in the data, and (3) assessing the robustness of the synthesis.

The first stage of developing a preliminary synthesis entailed extracting and collating data from the studies included in the review. A summary table was generated (Table 2.2), which included the following fields: author and year; study location; participant age and study sample; aim of the paper; the study design; length of follow-up; measures used; as well as the results of each study. In the second stage of the narrative synthesis, the studies were compared for similarities and differences. Relationships in the data were explored. The third and last stage of the narrative synthesis required assessment of how robust it was. To meet the requirement of robustness, articles were independently screened and checked for eligibility by the authors. No article was excluded due to quality, as required of a scoping review.

2.3 Results

2.3.1 Descriptive findings

The search identified 17 studies that followed-up children after inpatient psychiatric admission. All studies were quantitative, and no qualitative studies were found. Ten studies (59%) used a prospective research design (Blader, 2006a, 2006b; Gavidia-Payne et al., 2003; Green et al., 2007; Green et al., 2001; Ise, Schroder, Breuer, & Dopfner, 2015; Mattejat, Hirt, Wilken, Schmidt, & Remschmidt, 2001; Mayes et al., 2001; Sourander & Leijala, 2002; Stokes et al., 2003), while seven (41%) used retrospective designs (Carucci, Atzori, Balia, Danjou, & Zuddas, 2010; Fontanella, 2008; Fuchs et al., 2016; Healy & Fitzgerald, 2000; Jans et al., 2008; Nilsson & Hägglöf, 2005; van Bokhoven, Matthys, van Goozen, & van Engeland, 2006).

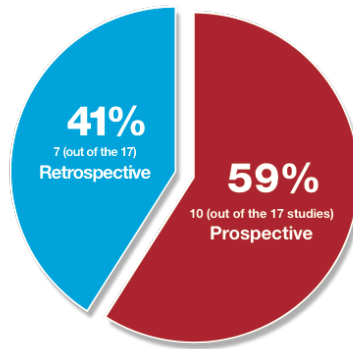


Figure 2.2 Study designs identified in the scoping review

Nine studies had more than one informant: two (Fontanella, 2008; Ise et al., 2015; Mayes et al., 2001; Sourander & Leijala, 2002) , three (Green et al., 2007; Green et al., 2001; Nilsson & Hägglöf, 2005; van Bokhoven et al., 2006) and four – parent, teacher, clinician, child (Gavidia-Payne et al., 2003) were used. Only three of the seventeen identified studies used comparative groups (Jans et al., 2008; Mattejat et al., 2001; Mayes et al., 2001). The summary of all identified studies is shown in Table 2.1.

Table 2.1 Summary of scoping review findings

First Author Year	Geographic Location	Study Design	Aim	Sample	Length of Inpatient Stay	Inpatient Treatment	Follow-up	Measures	Results
Fuchs, M. 2016	Austria (Tyrol)	Retrospective	To demonstrate frequency of admission and potential longitudinal shift	All child and adolescent patients diagnosed and treated 1989–2007 Sample of 987 Ages 2.83–17.98 years (mean 13.8 years) 20.7% ≤ 10 years 33.9% 11–14 years 51.5% female	Not indicated	Not indicated	5–23 years after discharge	Data matching with registry from adult psychiatric institutions	26% inpatient readmission when adult (5.6 times more than the national average). Readmission risk increased with more prior admissions, and tripled if admitted age ≥ 13 years. Previous diagnoses dictated adult diagnoses. 60% substance use problems were still evident when adult.
Ise, E. 2015	Germany (Cologne)	Prospective	To evaluate a parent-child inpatient setting that based treatment on evidence-based manuals	Consecutively admitted children (04/2007–04/2009) Sample of 66 Ages 3–10 years (mean 6.9 years) 74% male	4 weeks Weekends at home	1, 3, 4, 5 (daily social and attentional skills training) 6 (parent group behavioural training twice weekly, parent individual training 2–3 times a week, parent individual psychotherapy as needed, parent-child daily positive play and twice weekly coaching, weekly parent-child activity group, weekly family therapy 9	4 weeks after discharge	Child Behavior Checklist (parent), Teacher's Report Form, FBB-ADHS (ADHD rating scale), FBB-SSV (ODD rating scale), Self-rating scales for parents: Depression Anxiety Stress Scale, Individual Problem List, Self-Efficacy Scale, Parent Practices Scale, Problem Setting and Behaviour Checklist, Questionnaire on Judging Parental Strains	Inpatient treatment for parent-child resulted in improved child behaviour, found sustained at follow-up. Parents rated their parenting skills and mental health improved during inpatient admission, but only their self-efficacy in solving difficult parenting situations, continued to improve.
Carucci, S. 2010	Italy (specific area not indicated)	Retrospective	To describe the characteristics of children and adolescents with bipolar disorder, and study the possible influence of ADHD comorbidity on drug response and clinical outcome	Sample of 71 with DSM-IV diagnosis of bipolar (BP-I, BP-II, BP-NOS) Ages 6–18 years (no mean age) No gender given	Not indicated	Not indicated	6, 12 and 24 months after discharge	Medical charts, Children's Global Assessment Scale	Corroborated that there are different subtypes of paediatric bipolar disorder. Poorer outcome with comorbid ADHD. After 2 years BP-NOS had poorer outcome than BP-I and BP-II. BP-NOS had significantly earlier onset and more comorbid ADHD and ODD than BP-I.

First Author Year	Geographic Location	Study Design	Aim	Sample	Length of Inpatient Stay	Inpatient Treatment	Follow-up	Measures	Results
Fontanella, C.A. 2008	USA (urban and semi-rural populations)	Retrospective	To examine predictors of readmission	Medicaid patients consecutively admitted (07/1997–06/1998) to 3 private psychiatric hospitals Sample of 522 Ages 11–17.99 years 44.6% aged 11–13 years 53.8% female (overall)	1–5 days 20.7% 6–8 days 29.7% 9–17 days 25.1% >18 days 24.5% 11 days (estimated mean)	9 (86%)	1 month, 3 months and 1 year after discharge	Medical records, Medicaid claims, Area Resource File	Readmission rates for ages 11–13 years were 9.9% 1 month after inpatient discharge, 22.3% after 3 months and 44.6% after 1 year. Hospital provider, level of post discharge care and medication noncompliance, were the main predictors of readmission. Severe behaviour problems had a worse prognosis.
Jans, T. 2008	Germany (Würzburg)	Retrospective Comparative group for psychosocial outcome variables	To describe the long-term outcome of juvenile dissociative disorder in a clinical sample, and to assess psychiatric morbidity. Psychosocial functioning also assessed.	All patients treated for dissociative disorder in a Child & Adolescent Department of Psychiatry 1983–1992 27 (44% of 62 eligible) Mean age 12.7 years 63 % female 36 healthy controls	Not indicated	Inpatient 70% Outpatient 30% 1 mostly (15%) 3 mostly (59%) 6 mostly (41%) 7 mostly (19%)	12.4 years (mean) after discharge	Medical charts, semi-structured interview, Global Assessment of Functioning DSM111-R, Expert System for Diagnosing Mental Disorders, Heidelberg Dissociation Inventory, Structured Clinical Interview for DSM-IV, Social Adjustment Scale- Self Report	89% recovered or much improved at inpatient discharge. At follow-up 82.6% had a psychiatric disorder, 26.1% being dissociative disorder. 69.6% had fairly good psychosocial functioning.
Green, J. 2007	England and Wales (urban and rural populations)	Prospective	To correct the methodological limitations of previous research – of the process and outcome of inpatient child and adolescent mental health services	Sample of 117 at 1 year, from 150 consecutive admissions to 8 (4 child, and 4 adolescent) units over 15 months: ending 04/2002 Ages 3.4–14.8 years (mean 10.6 years) in child units. Ages 12.0–17.6 years (mean 15.4 years) in adolescent units. 54% male (more males in child units)	16.6 weeks (mean)	1, 2 (unclear), 3, 4, 5, 6, 9	1 year after discharge	Length of stay from ward staff Children's Global Assessment Scale, McMaster Family Assessment Device, Teacher's Report Form, Family Engagement Questionnaire, Strengths and Difficulties Questionnaire, Client Service Receipt Inventory, Kiddie-Schizophrenia and Affective Disorder Schedule, Salford Needs Assessment for Adolescents	After admission there was significant improvement, which was still apparent 1 year later. Better outcomes with child and parent therapeutic alliance, less family dysfunction and longer inpatient stay

First Author Year	Geographic Location	Study Design	Aim	Sample	Length of Inpatient Stay	Inpatient Treatment	Follow-up	Measures	Results
Blader, J.C. 2006a	USA (specific area not indicated)	Prospective	To determine the utilisation rates of particular pharmacotherapy strategies for aggressive behaviour, from preadmission to 12 months after discharge; and examine their association with post-discharge outcomes	Children admitted to an acute care psychiatric service for aggressive behaviour in the context of a disruptive behaviour disorder. Over 14 months beginning in 1998 Sample of 83 Ages 5–13 years (mean 9.37 years), 81 % male	16 days (median)	1 3 (mostly) 9	3, 6, 12 months after discharge	Clinical records, structured psychosocial history, telephone interview using Services Utilization Survey, Child Behavior Checklist (parent), New York Parent Rating Scale for Disruptive Behavior (Physical Aggression and Nonphysical Disruptive subscales)	Medication changes were frequently made during the year after inpatient discharge. Outcomes after discharge appeared linked to certain medication protocols
Blader, J.C. 2006b	USA (catchment area a large city, including suburbs)	Prospective	To develop a model of behavioural outcome in relation to family variables and their changes over time	Sample of 107 children Ages 5.11–13.62 years (mean 9.43 years) 78% male	13 days (median)	Not indicated	3, 6, 12 months after discharge	Prior psychiatric records, interviews with caregivers, telephone interviews with rating scales from teachers, Child Behavior Checklist (parent), Symptom Checklist-90-Revised (caregiver), Alabama Parenting Questionnaire, Caregiver Strain Questionnaire, Family Environment Scale, Parenting Stress Index, Recent Events Scale	Better outcomes when parents had much initial stress that decreased. If invariable low stress, improvement was less. Continual high parent stress had the worst outcome
van Bokhoven, I. 2006	Netherlands (specific area not indicated)	Retrospective	To describe the adolescent functioning of a disruptive behaviour disorder sample that had psychiatric treatment	Children who had received inpatient or day treatment in a unit specialised in treating disruptive behaviour disorder Sample of 47 Mean age 10.1 years 89.3% male	1.7 years (mean) Inpatient 61.7% Day patient 21.3% Inpatient and Day patient 17%	1, 4, 5 (social skills) 6 (parent training) 7	5.1 years (mean) after discharge	Caregiver: Child Behavior Checklist, Diagnostic Interview Schedule for Children – Version IV Teenager: Beck Depression Inventory, Sensation Seeking Scale, Interview using questions from Standard Survey Offenders and two questions from Questionnaire Data Juveniles, Youth Self-Report	38% had a favourable outcome, 34% did not do well. Individual variance was substantial

First Author Year	Geographic Location	Study Design	Aim	Sample	Length of Inpatient Stay	Inpatient Treatment	Follow-up	Measures	Results
Nilsson, K. 2005	Sweden (sparsely populated north)	Retrospective	To examine the long-term outcome of patients with anorexia nervosa, treated in child & adolescent psychiatry	Total population of patients treated for adolescent onset anorexia nervosa at child and adolescent clinics 1980–1985. Sample of 68 47% inpatients 12% inpatients and outpatients Ages 10–17 years (median 15.0 years) 100% female	Child & adolescent psychiatry (33%) 1 week (median) Paediatric care (35%) 48 hours (median)	1 (8%) 3 (40%) 6 (family therapy) 8 9 (12 months)	8 (median) and 16 (median) years post-discharge	Hospital records, Semi-structured interview, Global Assessment of Functioning DSM-111-R and DSM-1V, some questions from Steinhausen's follow-up interview for adolescent eating disorders, Symptom Checklist-90-Revised, Eating Disorder Inventory	Low mortality and 68% recovery rate by 1st follow-up, 85% recovered by 2nd follow-up but 37% had mental symptoms. The younger age group (10–13 years) did significantly worse than the older group. Somatic problems and paediatric inpatient admission initially were predictors of lower recovery from eating problems
Gavidia-Payne, S. 2003	Australia (68% of families resided in Melbourne metropolitan area; 32% in rural Victoria)	Prospective	To evaluate the effect of brief child and family inpatient admissions, using a range of standardised outcome measures	Families of children consecutively admitted to a State-wide Child Inpatient Mental Health Unit Sample of 29 (from 84 who agreed to participate) Mean age 9.34 years 72% male	4–8 weeks (mean 30.4 days) Weekends at home 28% family admissions	1, 2, 3, 4 5 (range, including physical therapy) 6 (parent and family therapy) 9	4 months post-discharge	Strengths and Difficulties Questionnaire (parents, teachers, referrers) Health of the Nation Outcome Scale for Children and Adolescents (referrers) Piers-Harris Children's Self-Concept Scale during admission (children) McMaster Family Assessment Device, Centre for Epidemiology Studies Scale (Depression), Parenting Scale, Parenting Sense of Competence Scale (parents)	Child behaviour and parenting skills improved significantly, but not family functioning. Depression of parents decreased. No change in child's self esteem
Stokes, J.M. 2003	USA (specific area/s not indicated)	Prospective A sample of 22 Rorschach protocols were chosen at random; scored by two psychologists unaware of the first coder's scores, and blind to the patient's scores. Post-discharge placements divided into two categories: day patient, special school; and home, outpatient	To test the predictive validity of the Rorschach Ego Impairment Index (E11-2) in a sample of children hospitalised for a variety of psychiatric disorders	Sample of 53 children from 4 different child psychiatric units Ages 5–12 years (mean 8.87 years) 75.5% male	63.5 days (mean) 35 days (median)	1, 2, 3, 4 5 (range including art therapy, psychodrama) 6 (family therapy) 7, 9	30 days and 120 days post-discharge	Medical chart data, Rorschach Ego Impairment Index Parent/Guardian: Devereux Scales of Mental Disorder, Schedule for Affective Disorders and Schizophrenia for School-age Children	The Rorschach Ego Impairment Index (E11-2) could be used with children. At 4 months post inpatient discharge, it appeared able to predict potential relapse and future problems, but not at 1 month post-discharge. No significant difference in outcome between more restrictive and less restrictive post inpatient discharge care

First Author Year	Geographic Location	Study Design	Aim	Sample	Length of Inpatient Stay	Inpatient Treatment	Follow-up	Measures	Results
Sourander, A. 2002	Finland (Turku, Satakunta and Seinäjoki)	Prospective	To describe the development of a previously studied cohort of psychiatric inpatients; but at additional follow-up timepoints and only those who had short-term admission	Sample of 46 from initial 86 consecutively admitted children and adolescents (01/1991–02/1993) to 3 hospitals Ages 4–15 years (mean 9.7 years) 80% male	4–6 weeks	1 (6%), 2, 3 (9%), 6, 9 (64%)	5 months, 1 year and 3 years post-discharge	Children's Global Assessment Scale (only 1 of the 3 hospitals), Rutter A2 Scale (parent/guardian), Rutter B2 Scale (teachers)	Most improvement was by inpatient discharge. Continual improvement but many symptoms at follow-up. 40% a good outcome. 30–40% somewhat positive outcomes. 20–30% poor outcomes. Worse outcome for conduct problems
Green, J. 2001	England (northwest)	Prospective	To investigate health gain and its predictors during inpatient and associated day patient treatment	55 consecutive admissions over 18 months to 2 inpatient child and adolescent units Ages 6–17 years (mean 11.4 years) 60% male	21,6 weeks (median) 45% mostly inpatients Weekends home (usually) 55% mostly day patients 40% moved between both	1, 2, 3, 4 6 (range)	6 months post-discharge	Children's Global Assessment Scale, U.K. Health of the Nation Outcome Scales for Children and Adolescents, Family Engagement Questionnaire, Teacher's Report Form, Child Behavior Checklist (Parent), McMaster Family Assessment Device (main caregiver), Empathy and Understanding Questionnaire (parent and child)	Significant improvement while an inpatient which was still evident at follow-up. Positive outcome primarily predicted by prior family functioning and therapeutic alliance of child
Mattejat, F. 2001	Germany (Mannheim and Marburg)	Prospective Controlled treatment study in which two randomised treatment groups (inpatient and home) were compared	To measure changes or differences between inpatient and home treatment groups	Sample of 68 from 2 psychiatric hospitals 1987–1989 Mean age 11 years, 9 months 64.7% male	Not indicated	Not indicated	2 years 1 month 5 years, 2 months (mean 3 years, 8 months) post-discharge	Interview for assessment using Marburg Symptom Scale, Rating of Psychosocial competency: adaptation at school or work	No significant differences between inpatient and home treatment (10–15% were eligible). Considerable improvement after treatment, with some deterioration by follow-up

First Author Year	Geographic Location	Study Design	Aim	Sample	Length of Inpatient stay	Inpatient Treatment	Follow-up	Measures	Results
Mayes, S.D. 2001	USA (urban, suburban and rural populations)	Prospective Comparative group	To assess improvement in psychological functioning in children admitted to a psychiatric inpatient unit for lengths of stay far shorter than in past studies. To develop a procedure for this that can be routinely used.	Sample of 110 consecutive admissions to a child psychiatric unit 01/1998–06/1998 Ages 2–13 years (mean 8.9 years) 71% male	4–80 days (median 13 days)	1, 3, 4, 5 6 (family therapy, parent- support group, parent-child group) 7, 9	1 and 6 months post- discharge	Global Family Environment Scale (social worker), Columbia Impairment Scale (parent version) via telephone interview at follow-up	Significant improvement in psychological functioning by inpatient discharge (93%). Some loss by follow-up, but no deterioration. Improved much more than a comparative group having mostly outpatient treatment. Family environment insignificant. Significantly poorer outcome for Behaviour Disorders
Healy, E. 2000	Ireland (Dublin)	Retrospective Sample compared with the age-related Irish population by employment status and emigration	To evaluate adult outcomes (particularly poor), of former child psychiatric inpatients	Direct information on whereabouts of 33 from 50 consecutive admissions 09/1978–07/1980 18 in follow-up assessment Children and adolescents Ages 4–16 years (mean 12 years) 68% male 66% < 13 years old, of which 85% male	1 week–15 months (median 6 months)	2, 3, 4 6 (family work) 7, 9	16 years post- discharge	Admission files and information from relevant agencies. Home visit: asked about past psychiatric history, Social Adjustment Schedule, Personality Assessment Schedule	A poor outcome (adult psychiatric disorder, unemployment, imprisonment, death) for 79% of 24 subjects where this information was available. Change of schools linked to positive outcome

Inpatient Treatment

- 1 Pharmacological
- 2 Therapeutic Milieu
- 3 Child individual psychotherapy
- 4 School
- 5 Child groups
- 6 Family/Parent work
- 7 Behaviour Therapy
- 8 Medical
- 9 Aftercare post discharge

2.3.2 Socio-demographic characteristics of studies

Of the 17 studies identified in the review, five were conducted in the USA (Blader, 2006a, 2006b; Fontanella, 2008; Mayes et al., 2001; Stokes et al., 2003). Eleven were from Europe, including three from Germany (Ise et al., 2015; Jans et al., 2008; Mattejat et al., 2001), two from the UK (Green et al., 2007; Green et al., 2001), and one from Austria (Fuchs et al., 2016), Italy (Carucci et al., 2010), the Netherlands (van Bokhoven et al., 2006), Sweden (Nilsson & Hägglöf, 2005), Finland (Sourander & Leijala, 2002), and Ireland (Healy & Fitzgerald, 2000). One study took place in Australia (Gavidia-Payne et al., 2003).

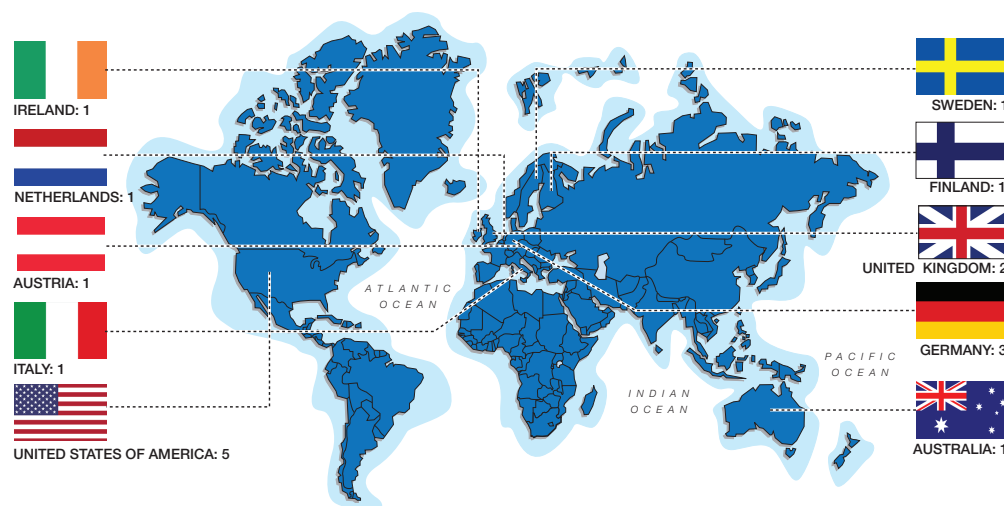


Figure 2.3 Geographic location of studies identified in the scoping review

Seven studies only involved children (Blader, 2006a, 2006b; Gavidia-Payne et al., 2003; Ise et al., 2015; Mayes et al., 2001; Stokes et al., 2003; van Bokhoven et al., 2006). With regard to the age profile of participants, Carucci and colleagues (2010) gave no mean age but was included in the review as it specifically stated results for ages ≤ 12 years. Three studies had a mean/median age of over 12 years (Fontanella, 2008; Fuchs et al., 2016; Nilsson & Hägglöf, 2005), but specifically mentioned results

obtained for patients ≤ 12 years. They were therefore also included in the review. The mean ages of the participants of the remaining 13 studies ranged between 6.9 years and 12.7 years. Twelve of the 17 studies had more male participants (Blader, 2006a, 2006b; Gavidia-Payne et al., 2003; Green et al., 2007; Green et al., 2001; Healy & Fitzgerald, 2000; Ise et al., 2015; Mattejat et al., 2001; Mayes et al., 2001; Sourander & Leijala, 2002; Stokes et al., 2003; van Bokhoven et al., 2006), nine of which had over 70% male participants. Three of the studies had more female participants (Fontanella, 2008; Fuchs et al., 2016; Jans et al., 2008), exceeding males by 1.5–13%. In one study (Nilsson & Hägglöf, 2005), all participants were female, while another failed to mention participant gender (Carucci et al., 2010).

2.3.3 Aims of studies

One of the 17 identified studies compared home treatment with inpatient treatment (Mattejat et al., 2001). Two tracked psychiatric readmission (Fontanella, 2008; Fuchs et al., 2016). Five assessed the predictive factors of improvement (Blader, 2006b; Gavidia-Payne et al., 2003; Green et al., 2001; Ise et al., 2015; Stokes et al., 2003). Nine followed patients in order to ascertain their progress in general (Green et al., 2007; Healy & Fitzgerald, 2000; Mayes et al., 2001; Sourander & Leijala, 2002), five concerning a specific diagnostic group: anorexia nervosa (Nilsson & Hägglöf, 2005); bipolar disorder (Carucci et al., 2010); disruptive disorder (van Bokhoven et al., 2006); dissociative disorder (Jans et al., 2008); and pharmacological use for aggression (Blader, 2006a). Green and colleagues (2007) also aimed to rectify the limited methods of prior studies, noted in reviews on this subject. Mayes and colleagues (2001) envisaged developing a routine assessment of psychological improvement.

2.3.4 Description of inpatient settings

Eight studies were of combined child and adolescent psychiatric units (Carucci et al., 2010; Fuchs et al., 2016; Green et al., 2001; Healy & Fitzgerald, 2000; Jans et al., 2008; Mattejat et al., 2001; Nilsson & Hägglöf, 2005; Sourander & Leijala, 2002), and one had separate child and adolescent units (Green et al., 2007). There were nine studies that examined one psychiatric unit, whilst the remainder studied between two

and eight units: Green et al. (2001) and Mattejat et al. (2001) studied two; Fontanella (2008) and Sourander and Leijala (2002) studied three; Nilsson and Hägglöf (2005) and Stokes et al. (2003) studied four; while Green et al. (2007) studied eight. One study (Carucci et al. (2010), did not indicate how many psychiatric units were studied. The number of beds per unit ranged between six and sixteen, with the number not mentioned in ten of the studies. In one study, parents (usually only the mother) and siblings (optionally) were also admitted (Ise et al., 2015). Another study admitted families (28%) with younger patients (Gavidia-Payne et al., 2003).

2.3.5 Length of inpatient stay

Length of inpatient stay varied significantly. The anorexia nervosa study reported one-week (mean) admissions (Nilsson & Hägglöf, 2005). Median stay was 11 days (estimated) in one study (Fontanella, 2008), while mean stay was 13 days in two studies (Blader, 2006b; Mayes et al., 2001) and 16 days in one (Blader, 2006a). Admission ranged between four and nine weeks in four studies (Gavidia-Payne et al., 2003; Ise et al., 2015; Sourander & Leijala, 2002; Stokes et al., 2003). Three studies had longer inpatient stays, with means of 16.6 weeks (Green et al., 2007), 21.6 weeks (Green et al., 2001), and 26 weeks (Healy & Fitzgerald, 2000). One study had a much longer mean stay of 1.7 years (van Bokhoven et al., 2006). Four of the identified studies did not mention the length of inpatient stay (Carucci et al., 2010; Fuchs et al., 2016; Jans et al., 2008; Mattejat et al., 2001).

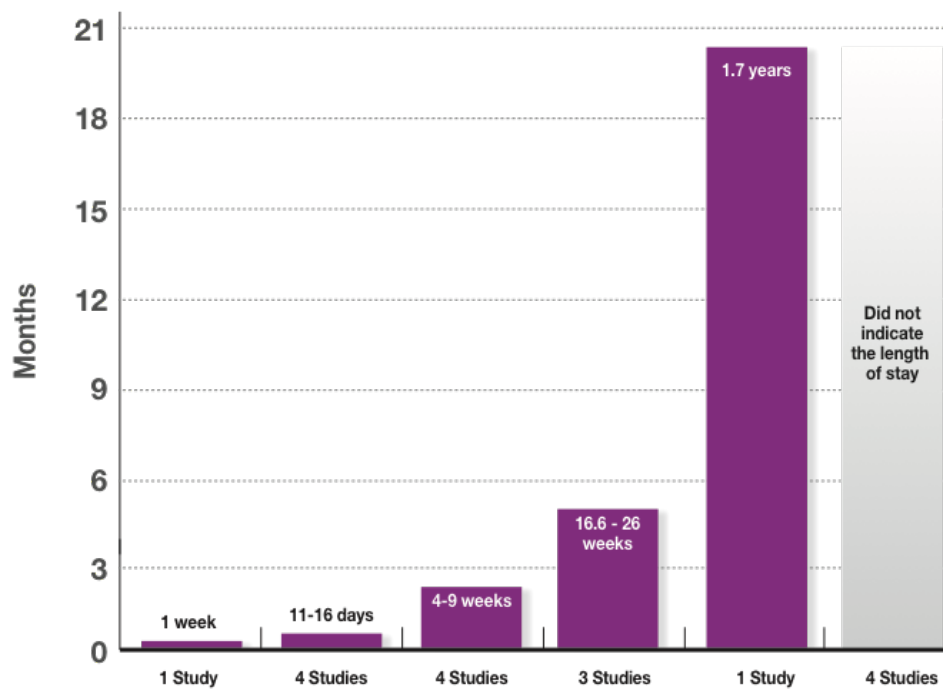


Figure 2.4 Length of inpatient stay before discharge, of studies included in the scoping review

2.3.6 Treatment

While treatment was not mentioned in four of the studies (Blader, 2006b; Carucci et al., 2010; Fuchs et al., 2016; Mattejat et al., 2001), a range of treatments were listed in the other thirteen studies. These included pharmacological therapy in eleven (Blader, 2006a; Gavidia-Payne et al., 2003; Green et al., 2007; Green et al., 2001; Ise et al., 2015; Jans et al., 2008; Mayes et al., 2001; Nilsson & Hägglöf, 2005; Sourander & Leijala, 2002; Stokes et al., 2003; van Bokhoven et al., 2006), though only for 15% in one study (Jans et al., 2008) and 6% in another (Sourander & Leijala, 2002); individual child psychotherapy in eleven (Blader, 2006a; Gavidia-Payne et al., 2003; Green et al., 2007; Green et al., 2001; Healy & Fitzgerald, 2000; Ise et al., 2015; Jans et al., 2008; Mayes et al., 2001; Nilsson & Hägglöf, 2005; Sourander & Leijala, 2002; Stokes et al., 2003), though only for 59% in one study (Jans et al., 2008); 40% (inpatients and outpatients) in the anorexia nervosa study (Nilsson & Hägglöf, 2005) and 9% in another study (Sourander & Leijala, 2002); school attendance on premises

in eight (Gavidia-Payne et al., 2003; Green et al., 2007; Green et al., 2001; Healy & Fitzgerald, 2000; Ise et al., 2015; Mayes et al., 2001; Stokes et al., 2003; van Bokhoven et al., 2006). Six studies had therapeutic child groups. Three named groups as social/attention training (Ise et al., 2015), social skills (van Bokhoven et al., 2006), group psychotherapy and recreational therapy (Mayes et al., 2001). Two studies stated having a comprehensive range of interventions (Gavidia-Payne et al., 2003; Stokes et al., 2003) including art and psychodrama (Stokes et al., 2003) and physical therapy (Gavidia-Payne et al., 2003), while Green and colleagues (2007) mentioned having psychosocial intervention. Six studies had a therapeutic milieu (Gavidia-Payne et al., 2003; Green et al., 2007; Green et al., 2001; Healy & Fitzgerald, 2000; Sourander & Leijala, 2002; Stokes et al., 2003) and five behaviour therapy (Healy & Fitzgerald, 2000; Jans et al., 2008; Mayes et al., 2001; Stokes et al., 2003; van Bokhoven et al., 2006), although only for 19% in one study (Jans et al., 2008). Eleven studies mentioned family work/therapy (Gavidia-Payne et al., 2003; Green et al., 2007; Green et al., 2001; Healy & Fitzgerald, 2000; Ise et al., 2015; Jans et al., 2008; Mayes et al., 2001; Nilsson & Hägglöf, 2005; Sourander & Leijala, 2002; Stokes et al., 2003; van Bokhoven et al., 2006), though only for 41% in one study (Jans et al., 2008); two a parent-child group (Ise et al., 2015; Mayes et al., 2001); two parent training (Ise et al., 2015; van Bokhoven et al., 2006); one parent-child positive play and coaching, as well as individual parent psychotherapy as needed (Ise et al., 2015); and one a parent support group (Mayes et al., 2001). Initial medical treatment was used in the anorexia nervosa study (Nilsson & Hägglöf, 2005). Care received after discharge was recorded in nine of the studies (Fontanella, 2008; Gavidia-Payne et al., 2003; Green et al., 2007; Healy & Fitzgerald, 2000; Ise et al., 2015; Mayes et al., 2001; Nilsson & Hägglöf, 2005; Sourander & Leijala, 2002; Stokes et al., 2003), although only for 86% in one study (Fontanella, 2008) and 64% in another (Sourander & Leijala, 2002).

2.3.7 Measures used in studies

Fifty-nine different measures were used in the 17 studies of the review. They assessed various outcomes which included: improved symptom control and psychological functioning of the child, improved family functioning, parenting skills and parent mental health, evaluation of therapeutic alliance and post inpatient care, psychiatric morbidity and readmission risk. Nine studies reviewed medical records (Blader, 2006a, 2006b;

Carucci et al., 2010; Fontanella, 2008; Fuchs et al., 2016; Healy & Fitzgerald, 2000; Jans et al., 2008; Nilsson & Hägglöf, 2005; Stokes et al., 2003) and six studies used interviews (without administering a measuring scale) to gather information (Blader, 2006a, 2006b; Healy & Fitzgerald, 2000; Jans et al., 2008; Nilsson & Hägglöf, 2005; van Bokhoven et al., 2006). The Child Behavior Checklist (CBCL) was used in five studies (Blader, 2006a, 2006b; Green et al., 2001; Ise et al., 2015; van Bokhoven et al., 2006) and the Children's Global Assessment Scale (CGAS) was used in four (Carucci et al., 2010; Green et al., 2007; Green et al., 2001; Sourander & Leijala, 2002). Two scales were each utilised in three studies, namely the McMaster Family Assessment Device (Gavidia-Payne et al., 2003; Green et al., 2007; Green et al., 2001) and the Teacher's Report Form (Green et al., 2007; Green et al., 2001; Ise et al., 2015). Five measures were each used in two of the studies, namely the Family Engagement Questionnaire (Green et al., 2007; Green et al., 2001), the Global Assessment of Functioning DSM- III-R (Jans et al., 2008; Nilsson & Hägglöf, 2005), the Health of the Nation Outcome Scales for Children and Adolescents (Gavidia-Payne et al., 2003; Green et al., 2001), the Strengths and Difficulties Questionnaire (Gavidia-Payne et al., 2003; Green et al., 2007), and the Symptom Checklist-90-Revised (Blader, 2006b; Nilsson & Hägglöf, 2005). Another forty-eight measures were used in only one study (Figure 2.5).

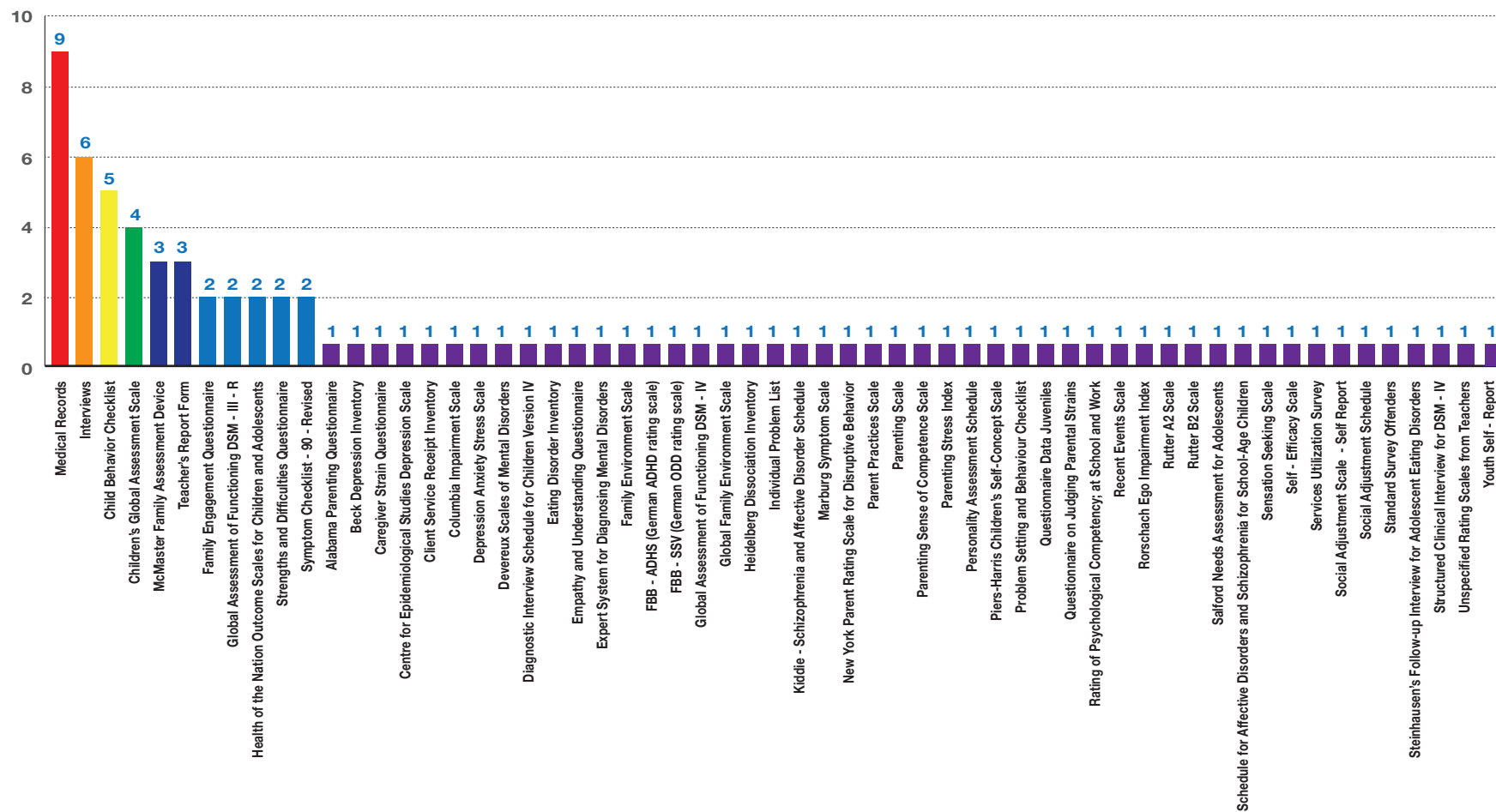


Figure 2.5 Measures used in studies included in the scoping review

2.3.8 Period of follow-up

The 17 identified studies were divided into short-term (1–4 months), medium-term (5–11 months), and long-term outcomes (1 year or longer) after discharge from an inpatient psychiatric unit. Three studies examined short-term outcomes (Gavidia-Payne et al., 2003; Ise et al., 2015; Stokes et al., 2003), one both short and medium-term (Mayes et al., 2001), and one only medium-term (Green et al., 2001). Two studies evaluated short, medium and long-term outcomes (Blader, 2006a, 2006b), while another included short and long-term (Fontanella, 2008) results. Two pertained to medium and long-term outcomes (Carucci et al., 2010; Sourander & Leijala, 2002). Seven studies assessed long-term outcomes (Fuchs et al., 2016; Green et al., 2007; Healy & Fitzgerald, 2000; Jans et al., 2008; Mattejat et al., 2001; Nilsson & Hägglöf, 2005; van Bokhoven et al., 2006).

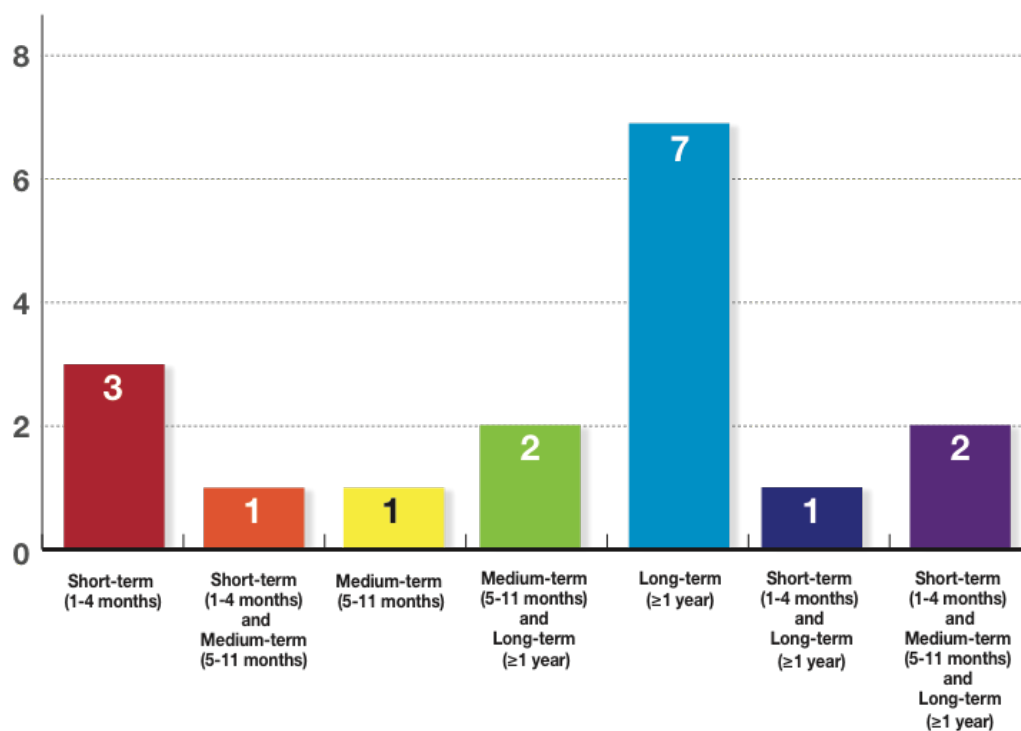


Figure 2.6 Period of follow-up after discharge, of studies in the scoping review

2.3.9 Outcomes

2.3.9.1 Short-term outcome (1–4 months) after inpatient discharge

Seven studies pertained to short-term (1–4 months) outcome (Blader, 2006a, 2006b; Fontanella, 2008; Gavidia-Payne et al., 2003; Ise et al., 2015; Mayes et al., 2001; Stokes et al., 2003). The benefit realised by inpatient admission was largely reported to be maintained at short-term outcome. However, there was an 11% loss of improvement after the first month in the short and medium-term study (Mayes et al., 2001), with or without psychiatric care. Despite family functioning not getting better and the child's self-concept appearing likewise, Gavidia-Payne and colleagues (2003) reported child and parent functioning to improve significantly, as did Ise and colleagues (2015). Gavidia-Payne and colleagues (2003) were evaluating the effect of brief (4-8 weeks) admissions, using a range of standardised outcome measures. Ise and colleagues (2015) aimed to evaluate the parent-child inpatient setting that based treatment on evidence-based manuals. Examining predictors of readmission, Fontanella (2008) found that the younger patients (aged 11–13 years) had a 9.9% readmission rate 1 month after inpatient discharge, while half of readmissions (22.3% aged 11–13 years) occurred within the first three months. The hospital provider, medication noncompliance and level of post-discharge care, mainly predicted readmission. Low-risk families and a change of living environment at discharge (particularly to a more structured facility) resulted in less readmission. However, Stokes and colleagues (2003) found levels of post-discharge care insignificant relative to outcome. Testing the predictive validity of the Rorschach Ego Impairment Index, they associated it with psychiatric deterioration between 1 and 4 months after inpatient discharge. A higher score indicated more ego impairment and it was correlated with the Devereux Scales of Mental Disorders (measuring behaviour). Aiming to determine the utilisation rates of certain pharmacotherapy strategies for children, Blader (2006a) learnt that children admitted for aggressive behaviour showed significant further improvement over the course of three months post-discharge, when treated with stimulant medication (54.1%) and Risperidone (41.9% took an atypical antipsychotic drug). However, they deteriorated significantly after three to six months, compared to children not treated with these medications.

2.3.9.2 Medium-term outcome (5–11 months) after inpatient discharge

Six studies captured medium-term outcome at 5–11 months (Blader, 2006a, 2006b; Carucci et al., 2010; Green et al., 2001; Mayes et al., 2001; Sourander & Leijala, 2002). Besides children treated with stimulant medication and Risperidone found to have deteriorated by the 6 months follow-up; those treated with antimanic medication (44%) had also deteriorated, when compared with those who were not treated with this medication (Blader, 2006a). Treatment with Lithium and SSRI (20.6%) medications appeared to not make a difference 6 months after admission, though they did at one year (Blader, 2006a). However, other studies found the gains attained during admission remained apparent: Green and colleagues (2001) saw the much-improved condition after inpatient admission still evident after 6 months, as did Mayes and colleagues (2001) despite some deterioration at the 1-month follow-up. Mayes and colleagues found that the patients showed far more improvement during the particularly short inpatient admission than those in a comparative group, who mostly received outpatient psychiatric care. Investigating health gain and its predictors during inpatient and associated day treatment, Green and colleagues (2001) reported therapeutic alliance of the child to be a prime predictor of positive outcome, as well as prior family functioning that was more satisfactory, but only after discharge. However, Mayes and colleagues (2001) found no difference in outcome between better or worse family conditions, while finding that behaviour disorders had significantly poorer outcomes. Sourander and colleagues (2002) determined that after short-term (4-6 weeks) admission, the most significant clinical improvement was after inpatient discharge, while it was 5 months thereafter by parental and teacher report. Less improvement was evident in the long-term outcome period.

2.3.9.3 Long-term outcome (1 year or more) after inpatient discharge

Twelve studies incorporated long-term outcome (Blader, 2006a, 2006b; Carucci et al., 2010; Fontanella, 2008; Fuchs et al., 2016; Green et al., 2007; Healy & Fitzgerald, 2000; Jans et al., 2008; Mattejat et al., 2001; Nilsson & Hägglöf, 2005; Sourander & Leijala, 2002; van Bokhoven et al., 2006).

Despite poor medium-term outcome, children who continued with Lithium (41.8% took antimanic medication) and SSRI medications (14.6%) showed significant behavioural

improvement at the one-year follow-up as opposed to the other children (Blader, 2006a). One year after inpatient discharge Green and colleagues (2007) could still see the high level of improvement found at discharge, with psychotic patients having improved the most and those with an eating disorder had further improved. Therapeutic alliance (parent and child) and less family dysfunction were associated with better outcomes, as well as longer inpatient stays. Aiming to develop a model of behavioural outcome in relation to family variables, Blader (2006b) correlated better one-year outcomes with parents who had high initial stress that subsequently decreased. The short and long-term readmission study (Fontanella, 2008), found that 44.6% of those aged 11–13 years (the younger patients) were readmitted by 1 year. Severe behaviour problems had a worse prognosis, with less readmission for those who had a shorter hospital stay.

With follow-up during the medium-term outcome period, as well as one and two years after inpatient admission, an identified study discovered bipolar disorder not otherwise specified had a worse outcome than bipolar I and bipolar II. (Carucci et al., 2010). It presented significantly at a younger age and with more comorbid ADHD and oppositional defiant disorder (ODD) than bipolar I. Sourander and Leijala (2002) found continual improvement one and three years after inpatient discharge, but less in the medium-term outcome period. Although half were functioning generally well, problem behaviour was mostly still noticeable, with conduct problems having a worse outcome. Likewise, Mattejat and colleagues (2001) saw much improvement after inpatient treatment, that decreased a little by 3-years 8-months (mean). There was no significant different outcome between inpatients and the 10–15% that were eligible for and had home treatment instead.

A disruptive disorder study (van Bokhoven et al., 2006) had similar amounts of positive (38%) and negative (34%) outcomes 5.1-years (mean) after discharge, with no significant difference between being only an inpatient or a day patient. Still longer outcome studies on dissociative disorder (Jans et al., 2008) and anorexia nervosa (Nilsson & Hägglöf, 2005) showed a loss of previous improvement. After 16 years, patients with anorexia nervosa had a recovery rate of 85% (increasing from 68% at the 8-year follow-up), though 37% still had mental problems. The younger 10–13-year-old age group had poorer outcomes than older patients. The juvenile dissociative disorder study (Jans et al., 2008) found that despite 89% of patients having recovered

or largely improved at discharge, a similar number (82.6%) had a psychiatric disorder (26.1% dissociative) 12 years later. However, psychosocial functioning was fairly good for 69.6% (mean). Poor outcomes (adult psychiatric disorder, unemployment, imprisonment, death), were also found for 79% of patients in a 16-year outcome study (Healy & Fitzgerald, 2000), though a change of schools was linked to a positive outcome. Aiming to demonstrate the frequency of admission, a high (26%) readmission rate was found in a 5–23-year post-discharge study, with diagnoses being predictable at follow-up (Fuchs et al., 2016). The ≥ 13 -year age group had a threefold higher adult readmission rate compared to those younger than 13.

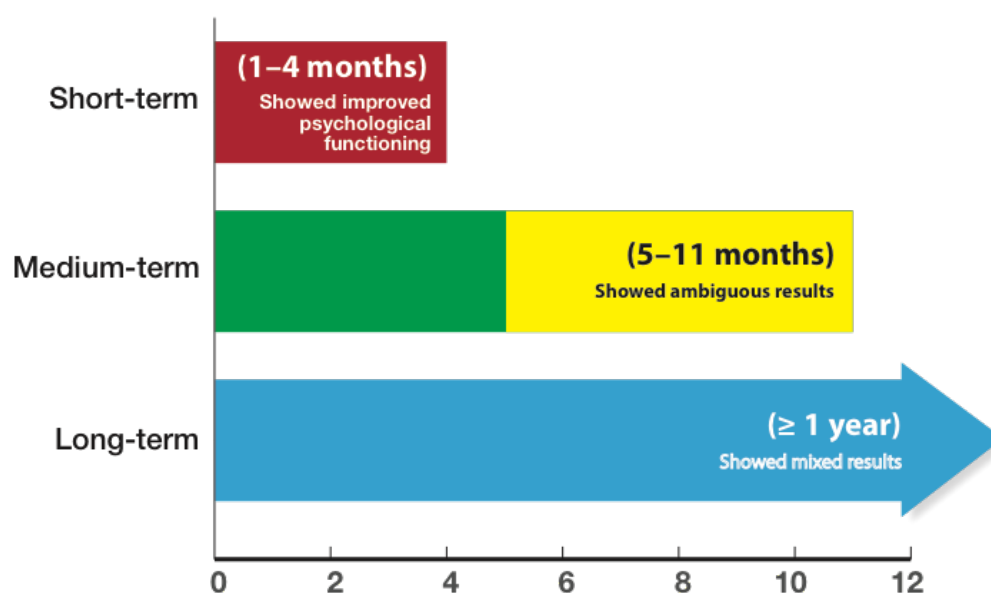


Figure 2.7 Visual summary of short, medium, and long-term outcomes in this scoping review

2.4 Discussion

There is a lack of systematic knowledge about the outcomes of children after inpatient psychiatric admission. This review aimed to determine short, medium, and long-term

outcomes of children after discharge from inpatient psychiatric admission internationally and focussed on all peer-reviewed publications between 2000 and 2017. Consistent with previous reviews (Blanz & Schmidt, 2000; Blotcky et al., 1984; Epstein, 2004; Pfeiffer & Strzelecki, 1990), psychiatric inpatient admission showed evidence of positive outcomes. However, improved psychological functioning was mostly found at short-term outcome, whereas medium and long-term outcomes showed mixed and unclear results.

2.4.1 Descriptive findings

The current review found a similar number of outcome studies to prior reviews. In keeping with previous findings, most were descriptive with no comparative group (Cornsweet, 1990). However, 59% were prospective studies in contrast to lower rates of prospective studies in earlier reviews (e.g. 26% identified by Pfeiffer and Strzelecki (1990) and 8% by Blotcky et al. (1984). Another encouraging observation in our data was the fact that nine of the seventeen studies recorded outcome data at admission, discharge, and follow-up (Blader, 2006a; Gavidia-Payne et al., 2003; Green et al., 2007; Green et al., 2001; Ise et al., 2015; Jans et al., 2008; Mattejat et al., 2001; Mayes et al., 2001; Sourander & Leijala, 2002) in contrast to an earlier report by Mayes and colleagues (2001), who could find no studies from 1990s that had data across these three critical timepoints.

2.4.2 Socio-demographic and geographical characteristics of studies

Previous reviews noted contrasting (Blotcky et al., 1984) and slight indications (Pfeiffer & Strzelecki, 1990) that demographic characteristics might have been related to outcomes. Age difference was found significant to outcome in all identified studies that had a mean age over 12-years (Nilsson & Hägglöf, 2005; Fontanella, 2008; Fuchs et al., 2016) and indirectly with bipolar disorder subtypes (Carucci et al., 2010).

The preponderance of male patients is in keeping with current international prevalence data (Biederman & Faraone, 2004; Oliver & Knight, 1984; Rice, Woolston, Stewart, Kerker, & Horwitz, 2002). The exception to this observation was the all-female sample in the anorexia nervosa study (Nilsson & Hägglöf, 2005), also in keeping with

international prevalence data suggesting that ten times more girls than boys developed an eating disorder (Mairs & Nicholls, 2016). Gender differences in outcome was significant in two of the studies: slightly higher significant ego impairment levels were obtained for females (Stokes et al., 2003). Fontanella (2008) found more female readmission (39% overall) by 12 months, as opposed to male (37%).

No studies in our review were from low- or middle-income countries (LMICs), reflecting the lack of child and adolescent mental health research and limited inpatient facilities in LMIC contexts (Kieling et al., 2011; Pedrini et al., 2012; World Health Organization, 2005). This supports the clear need to encourage outcomes-based research from LMICs, where the majority of children live.

2.4.3 Aims of studies

Almost a third of the identified studies set out to predict improvement factors post-discharge, reflecting the need to explore the circumstances of child psychiatric inpatient outcomes. However, only a few of the studies examined readmission, although mental health readmissions are not fully understood (Feng, Toomey, Zaslavsky, Nakamura, & Schuster, 2017). It was of interest that there was not a more overt focus on functional outcomes (as opposed to symptom-based outcomes) in any of the research studies. We were also struck by the absence of studies that aimed to examine family, caregiver, or child perspectives about outcomes. These are all important areas for future research.

2.4.4 Description of inpatient settings

Although the number of beds were often not reported, inpatient units characteristically had small numbers of patients (Sheerin et al., 1999). Contributing to relatively few admissions are the frequent complexity of cases (Dhansay, 2012), as well as the high staff to patient ratio required. Virtually half of the studies had combined child and adolescent units. We acknowledge that inpatient units around the world may look and 'feel' quite different, thus compounding the challenge of 'standardising' the intervention in any way. We propose that the international community consider creating some

universal 'metrics' to describe inpatient settings that might allow like-for-like comparison in future.

2.4.5 Length of inpatient stay

Of the 12 identified studies that indicated the length of inpatient stay, one third had a stay of 16 days or less (mean 12 days) and another third had an inpatient stay of between 4 and 9 weeks (mean 6 weeks). This is indicative of acute and short-term inpatient stay gaining popularity due to rising costs and an aim to minimise restrictiveness (Hersov, 1994). Inpatient treatment came to be seen as only one part of a continuity of care (Blanz & Schmidt, 2000; Curry, 1991; Epstein, 2004) with treatment incorporated into the home and community (Blanz & Schmidt, 2000; Curry, 1991; Epstein, 2004). While only children who were extremely unwell became more likely to be admitted (Blanz & Schmidt, 2000; Cornsweet, 1990; Ney et al., 1988; Sheerin et al., 1999), some units chose children thought more inclined to improve (Ney et al., 1988). Blanz and Schmidt (2000) highlighted that an ideal length of stay is unknown. Three of the identified studies had longer inpatient stays of between 16.4 and 26 weeks (mean 21.4 weeks), while a much longer stay (mean 1.7 years) was found in one study that incorporated a large amount of day patient treatments. Numerous variables could influence admission length, such as the patient's diagnosis (Sheerin et al., 1999), difficulties with post-discharge placement (Oliver & Knight, 1984) or even staff's attachment to patients (Ney et al., 1988). Similar to earlier comments, we acknowledge that it is virtually impossible to make a direct comparison between very short-term admissions (e.g. <2 weeks), short-term (e.g. <2 months) and longer-term admissions. The goals of different durations of admissions are typically quite distinct, and outcomes expectations may therefore also be quite different.

2.4.6 Treatment

Following an historical lack of knowledge of inpatient treatment (Blanz & Schmidt, 2000; Blotcky & Dimperio, 1991; Blotcky et al., 1984; Curry, 1991; Epstein, 2004; Pfeiffer & Strzelecki, 1990) and CAMH treatment in general (Zhou et al., 2020), a range of treatments were typically utilised, with pharmacological, individual

psychotherapy and family work most common. Child and parent therapeutic alliance was found to predict positive outcome in two of the identified studies (Green et al., 2007; Green et al., 2001), yet how it interfaces with treatment is not fully understood (Karver, Monahan, Nadai, & Shirk, 2018). In keeping with the emerging theme about the highly heterogeneous nature of inpatient admission for children, studies included in this scoping review underlined the highly diverse nature of interventions provided. Here too we recommend that international agreement should be reached on a standardised system to document 'treatment' or 'intervention' components included in any outcomes studies

2.4.7 Measures used

Measuring variables for insight into psychiatric outcomes is challenging (Sheerin et al., 1999) as evidenced by the vast number of measurements in the 17 identified studies, most of which were used only once. There is a need to identify or develop measurements of outcome that would be suitable to preadolescent inpatient settings. However, such an activity requires various considerations including (a) age and developmental range of young people; (b) heterogeneity in presentation, diagnoses and formulations of patients; (c) need to consider different levels of outcome (individual psychopathology, functioning, educational, family, community); (d) variation in the nature and activities of inpatient units around the world; (e) highly variable activities, clinical support and interventions to young people after discharge from inpatient units that will make it very difficult to determine what the 'active ingredients' were that led to a specific outcome; and (f) arguably the most important – the need to understand the outcome priorities of young people and families. Notwithstanding these multilevel challenges, there would still be value in identifying, developing, and/or agreeing on some standardised tools for a 'preadolescent inpatient outcomes toolkit' that can at least introduce some consistency and comparability across studies. Perhaps there could also be a consensus process to agree about core demographic and functional measurements that would make it easier in future to compare like-for-like.

2.4.8 Outcomes of reviewed studies

2.4.8.1 Short-term outcome (1–4 months) after inpatient discharge

Short-term outcome showed mostly improved psychological functioning. A range of individual and group therapies were employed, with significant sustained child and parent improvement found in the identified studies (Gavidia-Payne et al., 2003; Ise et al., 2015) where families could reside in the unit if needed, with additional parent group treatment. This corroborates findings of a review of parent training programmes; where cognitive and behavioural techniques have been found to empower parents and decrease unwanted child behaviours, resulting in statistically significant less unhelpful parenting styles (Furlong et al., 2012). Yet in an identified study, Gavidia-Payne and colleagues (2003) noted that the child's self-concept appeared unaffected during inpatient admission. Similarly, Sheerin and colleagues (1999) established that self-esteem improved significantly only for children with depressive symptoms. Likewise, in an identified study the Rorschach Ego Impairment Index was discovered to be able to predict susceptibility to psychiatric deterioration occurring between 1 and 4 months after inpatient discharge (Stokes et al., 2003). As Stokes and colleagues (2003) commented, it makes sense that children with ego impairments would respond well to the routine setting of a psychiatric unit, but would not manage if it was taken away from them. While Stokes and colleagues (2003) found the post-discharge living environment insignificant, Epstein (2004) remarked how studies reflect the importance of a positive post-discharge environment for the patient's adjustment, superseding inpatient improvement. Understandably then, an identified study (Fontanella, 2008) discovered that most readmissions occurred within three months of inpatient discharge, with less following a change of environment. Likewise, a study outside this review reported that 33.9% of 5–12-year-old children were readmitted within one year of acute care, 81% in the first trimester (Blader, 2004). Conduct problems and poor parent-child relationships as well as follow-up care increased the likelihood of readmission. Similarly, Robertson and Friedman (1979) found that children older than 10 years improved if they did not go back to live at home after they completed day treatment.

2.4.8.2 Medium-term outcome (5–11 months) after inpatient discharge

Medium-term outcome produced ambiguous results. This may be due to indications from numerous studies that children have a worse prognosis if discharged 6–12

months after treatment, possibly starting to regress soon after inpatient discharge (Kolko, 1992). An identified study (Blader, 2006a) attributed the worsening of behavioural symptoms to the frequent termination or changes of medication that were usually made 3–6 months after discharge. Furthermore, 73.68% of children treated for aggression began three or more medications between 6 months and a year, highlighting a need for further containment. The significance of positive family variables to medium-term outcome was found to be contradictory (Green et al., 2001; Mayes et al., 2001), although prior reviews saw that they appeared to accommodate improved outcomes, while negative family variables were connected to poor outcomes (Blotcky et al., 1984; Pfeiffer & Strzelecki, 1990). However, these associations have had minimal study (Blader, 2006b). Measurement and analysis of family functioning is difficult, with multiple variables needing to be taken into account (Blotcky et al., 1984). For instance, family stress has been found to correlate with the attention deficit hyperactivity disorder (ADHD) symptoms of children, reported by an identified study (Blader, 2006b) and Guerro-Prado and colleagues (2015).

2.4.8.3 Long-term outcome (1 year or more) after inpatient discharge

Long-term outcomes showed mixed results. The identified study with a one and three-year follow-up (Sourander & Leijala, 2002) ascertained that approximately half of the former short-term inpatients had a CGAS score over 61, meaning they were functioning generally well (Shaffer et al., 1983). This result closely resembles outcomes commonly found after psychiatric treatment (Sourander & Leijala, 2002). The review by Blotcky and colleagues (1984) studied the timelines of follow-up, finding fluctuations during the first two years after discharge. The impression was that of a slow improvement for half, which would result in them coping adequately as adults. While a consequence of child inpatient stay may be gradual (Sheerin et al., 1999), these sleeper effects (Sheerin et al., 1999; Sourander & Leijala, 2002) were most apparent in the three-year outcome studies (Mattejat et al., 2001; Sourander & Leijala, 2002) of this review. However, findings in more long-term outcome studies, were instead suggestive of a decline in long-term functioning. Possible explanations might be the discontinuation of follow-up care, transition to secondary school and

developmental changes associated with becoming a teenager, which are all likely to occur during this outcome period.

The magnitude of mental health problems is largely unrecognised the world over, with a consequent lack of resources for those who require mental health care and who face numerous obstacles and challenges in society (Zhou et al., 2020). Notably, the mortality of people with severe mental illness is 2–3 times above the norm (De Hert et al., 2011). The high readmission rate found in the 5–23-year-old outcome study (Fuchs et al., 2016) reflects the high percentage of mental health problems found to persist into adulthood (Gore et al., 2011; Jans et al., 2008; Mairs & Nicholls, 2016). A study (Brieger, Bloink, Sommer, & Marneros, 2001) referenced in the identified study by Fuchs and colleagues (2016), reassessed child and adolescent psychiatric patients 5–17 years after index hospitalisation. Approximately 40% of the cohort (as opposed to 25% of the control group) could be assigned a psychiatric diagnosis, 25% of which had contacted psychiatric services after the age of 18. Likewise, the outcome of the identified anorexia nervosa study (Nilsson & Hägglöf, 2005) reflects previous anorexia nervosa studies, where between 60–90% of the patients will have mostly recovered at follow-up (Mairs & Nicholls, 2016). While childhood onset is suspected to have a poorer prognosis than that of adolescents (Mairs & Nicholls, 2016), improved family dynamics has been found the key to remission of anorexia nervosa (Ciao, Accurso, Fitzsimmonds-Croft, Lock, & Le Grange, 2015). Despite relapse being uncommon (Gowers et al., 2010; Mairs & Nicholls, 2016), half will acquire a comorbid psychiatric illness in adulthood (Mairs & Nicholls, 2016).

It is particularly noteworthy that although an identified 16-year outcome study (Healy & Fitzgerald, 2000) mostly found poor outcomes, it reported that a change of schools was associated with positive outcome. Mental health problems have been found closely associated with poor school achievement (Ogilvie, Head, Parekh, Heintzman, & Preyde, 2019), with anxiety regarding school established to be largely responsible for youth psychiatric inpatient admission (Preyde, Parekh, Warne, & Heintzman, 2017); while school disengagement has been linked to psychosocial problems in adolescence and adults (Henry, Knight, & Thornberry, 2012). Behavioural problems are the most common presentation in child inpatient psychiatry (Dhansay, 2012), and the most frequent child psychiatric diagnosis is conduct disorder, with problem behaviour often continuing into adulthood (H. Green, McGinnity, Meltzer, Ford, &

Goodman, 2005). Places of education that do not cater for children with behavioural problems have been significantly linked to poor outcome (Robertson & Pikholtz, 1987). Externalising disorders, particularly those that began at a young age, have largely been found to have a negative impact on school completion (Esch et al., 2014; Veldman, Reijneveld, Ortiz, Verhulst, & Bültmann, 2015), tertiary education and employment (Veldman et al., 2015), as well as resulting in poor socio-economic outcomes in adulthood (Fergusson, Horwood, & Ridder, 2005).

2.5 Limitations

Even though this is, to our knowledge, the first scoping review in the last 2 decades, we acknowledge a number of potential limitations. While extensive databases were searched and articles relating to child psychiatric inpatient outcome thoroughly screened, we recognise that there may be articles that were missed due to the specific search terms that were used. We also accept that the inclusion of only English publications may have excluded potentially relevant publications. However, given existing resources, it was not possible to translate the German publications. We acknowledge that only 17 international studies since 2000 were identified, findings of which showed highly heterogeneous samples, use of a wide range of outcome measures with no standardised measures used across studies, and significant variability in timepoints for outcome measures. Consistency and comparability were therefore compromised, which made interpretations of the findings difficult. Finally, we also acknowledge the clear limitation that the literature searched, included publications only between 2000–2017, and accept that some valuable outcomes-based literature may have been published since 2017. We acknowledge this limitation in the context of the COVID-19 pandemic which affected not only clinical and academic services, but also the families.

2.6 Conclusion

Outcome data of preadolescent psychiatric inpatient treatment remain limited and suggest unclear medium and long-term outcomes. Inconsistent lengths of inpatient stay and follow-up period, lack of uniform measures and unblinded reports, sparse

community comparison and comparison with other treatment modalities, may explain some of the variable findings. Yet the emerging picture is that of substantial short-term improvement that is somewhat sustained in the medium and immediate long-term (1-3 years after inpatient discharge). However, marked deterioration is seen in much longer-term outcome studies. The reasons for this are not clear from the wide spectrum of identified studies, although the literature leaves clues around factors that may contribute to sustained positive outcomes after admission. These include sufficient follow-up care and appropriate home and educational environments. Future outcomes research will require uniformity of outcome variables and measurements, careful consideration of contrast/control conditions, and international consensus on timeframes for outcome studies. Importantly, all studies in this scoping review were from high-income countries suggesting that further psychiatric outcome research from low- and middle-income settings is clearly needed. Furthermore, qualitative studies could prove valuable to ensure the inclusion of family and young people's voices about outcomes after inpatient psychiatric admission.

2.7 Chapter summary

Only a few children are admitted for psychiatric inpatient care. A review in 2000 showed mixed results about outcomes from admissions and highlighted a number of challenges with outcome studies. We aimed to describe outcomes and follow-up of child psychiatric admissions since the previous review, in the existing body of literature. Two reviewers independently searched EBSCOhost and Scopus (January 2000 – February 2017), using keywords 'inpatient'; 'psychiatry'; 'psychiatric unit'; 'mental health'; 'children'; 'treatment outcome/s'; 'follow-up'; 'secondary care' to identify studies examining child (0–12 years) psychiatric inpatient outcomes. All peer-reviewed full-text primary data studies published in English, where children admitted to psychiatric inpatient units were followed up post-discharge, were included. Seventeen studies were identified using PRISMA (11 European, 5 from the United States of America, and 1 Australian). Prospective studies made up 59% of the study designs. Only 3 studies had comparison groups. Measurements used differed widely – of the total of 59 measurement tools, 48 were utilised only once. The most frequently used measures were the Child Behavior Checklist (n= 5), and the

Children's Global Assessment Scale (n= 4). Significant improvements were reported at discharge and was maintained in short-term follow-up (1–4 months) studies. However, medium-term (5–11 months) and long-term follow-up studies at 1 year or greater, showed mixed results. Outcome data of child psychiatric inpatient treatment remain limited and suggest unclear long-term outcomes. The findings are very difficult to interpret because of the great heterogeneity in populations, durations, and measurements. Further research, particularly from low- and middle-income countries, is warranted. However, uniformity in the research process, as well as qualitative studies are needed.

Chapter 3

“A turn in the road, but still a rough journey”. Parent and child perspectives of inpatient psychiatric admission.

3.1 Background

Approximately 20% of children and adolescents have mental health disorders (Kieling et al., 2011) and between 50–75% of adult mental illness commences before the age of 18 (Jones, 2013). In addition, half of children and adolescents using psychiatric services live with a mentally ill parent (Mattejat & Remschmidt, 2008). However, in most countries, fewer than 50% of children with mental health problems receive any treatment. In low- and middle-income countries (LMICs) this ‘treatment gap’ is often in excess of 90% (Demyttenaere et al., 2004; Patel et al., 2010; Saxena, Thornicroft, Knapp, & Whiteford, 2007). Where services do exist for child and adolescent mental health (CAMH), countries rarely evaluate the outcome of treatments in a systematic way, leading to an ‘information gap’ (World Health Organization, 2005). Pedrini and colleagues (2012) emphasised how this information gap could hinder clinical and research progress, given that knowledge of the outcomes and quality of care and interventions is needed (a) to ensure a high quality of care, (b) to ensure interventions are evidence-based, (c) to generate evidence for interventions where it does not exist, and (d) to provide data for health economic and policy development purposes.

Globally, information about inpatient preadolescent psychiatric units is limited. Young people may be admitted to inpatient psychiatric units for various reasons, including to receive detailed assessment or treatment away from the family home, in response to escalation of symptoms despite intensive outpatient treatment, or to participate in controlled trials of specific interventions (J. Green & Worrall-Davies, 2008). Inpatient admission may have ‘risks’ and ‘benefits’ (J. Green & Worrall-Davies, 2008). Most studies suggest that intensive outreach can reduce the need for inpatient admission,

but cannot replace it (J. Green & Worrall-Davies, 2008). Interestingly, only half of high-income countries (HICs) have dedicated inpatient units for children with mental health disorders. In LMICs very few dedicated units for CAMH exist (World Health Organization, 2005). In Africa, a survey of available services identified only six inpatient units that admitted preadolescent children (Dawson-Squibb & Gasela, 2017). One was in Uganda, two were in Egypt and three in South Africa (Weskoppies Adolescent and Child Unit in Pretoria, a Children's Ward at Tara Hospital in Johannesburg, and the Therapeutic Learning Centre in Cape Town).

Research regarding the outcomes of child and adolescent psychiatric inpatients appears insufficient and neglected. Where data are available, the majority of studies focus on adolescents. As a result, knowledge about outcomes after admission to a preadolescent inpatient unit remains very limited. Past reviews (Blanz & Schmidt, 2000; Blotcky et al., 1984; Epstein, 2004; Pfeiffer & Strzelecki, 1990) claimed inpatient admission to be largely beneficial. However, many of the studies were found to have had questionable methods and indistinct outcomes (Blotcky et al., 1984; Epstein, 2004; Pfeiffer & Strzelecki, 1990). As outlined in Chapter 2, we set out to examine child (0–12 years) psychiatric inpatient outcomes in a recent scoping review of all studies published subsequent to the previous review published in 2000. We identified a total of 17 peer-reviewed papers that met inclusion criteria and found that the positive effects of inpatient admission were most evident for short-term (1–4 months) outcomes. Findings on medium (5–11 months) and long-term (1 year or more) outcomes were much more mixed and unclear, with deterioration evident in long-term studies. The identified studies were predominantly quantitative, and most did not have a comparative group. Study samples were highly heterogeneous and 59 different outcome measures were used with only 11 used in more than one study. Research challenges included low patient numbers, inevitable patient variability, as well as the unique and highly variable characteristics of inpatient units (Sheerin et al., 1999). Apart from these obvious methodological challenges, dynamic developmental considerations complicate any such research. For example, there are suggestions that children may have fluctuating symptom profiles (Blanz & Schmidt, 2000; Pfeiffer & Strzelecki, 1990), and the highly dynamic developmental stages of childhood need to be taken into account (Blotcky et al., 1984; Cornsweet, 1990). Additionally, environmental influences have been deemed considerable (Cornsweet, 1990).

Based on the findings of the scoping review (as outlined in Chapter 2), we made a number of next step recommendations. These included the need for international consensus on key variables for the measurement of outcomes, identification of standardised outcome measures, and agreement on levels of outcomes to be explored (e.g. child, family, education, community). However, given the lack of current consensus on outcomes, the findings also raised the importance of seeking the perspectives of families and children (Husky et al., 2018) about (a) their experience of inpatient admission, (b) how they viewed their own short, medium, and long-term outcomes, and (c) what they perceived to be important factors that influenced their outcomes post-discharge. We propose that such qualitative findings, based on the lived experience of young people and their families, could also inform outcome measurement for future studies.

The research question in this chapter was therefore to determine the short, medium, and long-term outcomes of children after discharge from an inpatient psychiatric unit in Cape Town, South Africa, as perceived by the child and their family.

3.2 Methods

3.2.1 Study design

The study used a qualitative descriptive approach to explore parental and child perspectives of (a) their inpatient experience, (b) what improved/least improved during admission, (c) what improved/least improved after discharge, and (d) what changed after discharge – including what they felt helped or hindered their progress after discharge from a preadolescent psychiatric inpatient unit in South Africa.

3.2.2 Recruitment

Following ethical approval from the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee (HREC Ref 585/2018), permission to conduct the study was obtained from the clinical head of the inpatient unit in the Western Cape and the Research Review Committee of the Red Cross War Memorial Children's Hospital (RXH: RCC169). All clinic registers and inpatient files for the years

2009–2017 were searched for contact information of families. Data were provided to the clinical head, who shared data with the primary clinical contacts of potential participants. Primary clinical contacts were the clinical team members who were actively working with proposed families or were the most recent clinical team members to have worked with families. Employing convenience sampling, eligible families were contacted by clinical team members to ask if they would be interested to participate in the study. Thirty-four families were approached, of which twenty-four families were reached. Families who indicated willingness to participate were asked their contact preference for invitation to the study. The primary researchers subsequently invited twelve of these families to participate, ten of whom accepted. Reasons for non-participation of contacted families included time constraints, ill-health, and not living in Cape Town anymore

3.2.3 Setting and data collection

All participants, both child inpatients and their parents, were given an information sheet, informed about the study, and invited to a face-to-face semi-structured individual interview (SSII) lasting approximately 40 minutes. Prior to free and voluntary participation, participants 18 years and older gave informed written consent, while those younger gave informed written assent. Interviews were conducted in a quiet, private room on the premises of the Division of Child & Adolescent Psychiatry, University of Cape Town. The interviews were conducted by a psychology research assistant who had not been involved in any aspect of inpatient care of any of the participants. The research assistant informed participants of her independence from the inpatient clinic. Children and parents completed a demographic questionnaire and were interviewed separately. All interviews were conducted in English, which was indicated by all families as their home language, and were audio recorded with participant consent. An interview schedule with five open-ended questions was used to provide a basic structure to the SSII. The questions (child version) included 1) When you were at the (name of psychiatric unit), what things got better or worse for you?; 2) After leaving the (name of psychiatric unit), what things got better or worse for you?; 3) What helped or made things difficult for you after leaving the (name of psychiatric unit)?; 4) What was it like to be at the (name of psychiatric unit)?; 5) Are there some

things that you remember about the (name of psychiatric unit) that you could tell me about? No other materials or measures were used. To ensure anonymity and confidentiality, all participants were allocated a number, and pseudonyms were used in the transcriptions. Families were given ZAR100 (~US\$7) as a thank-you for their participation.

3.2.4 Data analysis

Audio recordings of the interviews were transcribed verbatim by an independent researcher and qualitative data were analysed using thematic analysis, as outlined in six phases by Braun and Clarke (2006): familiarisation with the data, generating initial codes, reviewing themes, defining and naming themes, producing the report. The first author identified and coded generated categories (Schurink, Fouché, & de Vos, 2011) from all transcripts to identify emerging themes. A second coder, with high-level experience in qualitative analysis, independently coded 30% of the transcriptions for emerging themes. Identified codes and emerging themes were then revised and refined. The findings were interpreted within the context of existing literature on outcomes of children after inpatient psychiatric admission.

3.2.5 Trustworthiness

The study performed thematic analysis of data which may be open to bias. To reduce potential bias and to increase trustworthiness, we (a) invited all families who had previous inpatient admission (to avoid pre-selecting those with positive experiences or outcomes), (b) ensured that interviews were conducted by a research assistant who had no link or association with the inpatient unit or staff, and (c) ensured that a senior researcher with no previous involvement in the inpatient unit independently was used to code 30% of transcripts.

3.2.6 Ethics

The ethical principles of autonomy, beneficence, justice, and non-maleficence were ensured in the study. Research Ethics Clearance was provided by the University of

Cape Town (HREC Ref 585/2018) and Red Cross War Memorial Children's Hospital (RXH: RCC169). Informed consent/assent was obtained from all participants in the study.

3.3 Results

3.3.1. Demographic characteristics of participants

Participants consisted of a subset of all children who were inpatients at a psychiatric unit in the Western Cape, South Africa between 2012 and 2017, and their parents.

The final group of participants consisted of ten parent-child dyads and are shown in Table 3.1. Of these ten, two of the children were admitted as psychiatric inpatients in 2012 ($n = 2$; 20%), two in 2013 ($n = 2$; 20%), one in 2014 ($n = 1$; 10%), two in 2015 ($n = 2$; 20%), one in 2016 ($n = 1$; 10%) and two in 2017 ($n = 2$; 20%). The period after inpatient discharge ranged from 15 months to 8 years. The sample was predominantly males ($n = 7$; 70%) including one birth-assigned female who now identifies as male. Ages during inpatient admission ranged between 7 and 14 years ($M = 10,5$; $SD = 2$) with the majority in the 10–12-year-old range ($n = 7$; 70%). Age at the time of research participation ranged from 8 to 19 years ($M = 14,9$; $SD = 3,1$), with most of the participants in the 15–17-year-old range ($n = 6$; 60%). Participants represented a range of diagnoses, including anorexia nervosa; attention deficit hyperactivity disorder (ADHD); autism spectrum disorder (ASD); epilepsy; generalised anxiety disorder (GAD); major depressive disorder (MDD); obsessive-compulsive disorder (OCD); oppositional defiant disorder (ODD); separation anxiety; specific learning disorder; Tourette's Syndrome; trichotillomania. The majority of parents were mothers ($n = 8$; 80%), half of which were single parents. One father ($n = 1$; 10%) participated, and there was one set of mother and father ($n = 1$; 10%) who participated together.

Table 3.1 Participant demographics

Participant number Present Age Age	Inpatient Age	Sex	Length of Inpatient Stay	Diagnosis at Inpatient Discharge	Subsequent Additional Diagnosis	Period after Inpatient Discharge	Participant Parent
TS001 8 years	7 years	Male	5 months	ADHD ODD	Attachment Disorder Anxiety	15 months	Mother
TS002 12 years	8 years	Male	6 months	ADHD	ASD OCD MDD GAD	5 years	Mother
TS003 14 years	12 years	Female	9 months	MDD Separation Anxiety Specific Learning Disorder		2 years	Mother and Father
TS004 15 years	12 years	Male	4 months	GAD Trichotillomania ASD	Transgender	3 years	Mother
TS005 16 years	12 years	Male	10 months	Anorexia Nervosa Body Dysmorphic Disorder MDD	Social Anxiety	4 years	Father
TS006 19 years	13–14 years	Male	2 months Day patient 1 month	ASD		6 years	Mother
TS007 17 years	10 years	Female	6 weeks	ADHD Specific Learning Disorder OCD Tourette Syndrome	Depression	7 years	Mother
TS008 17 years	9–10 years	Male	1st 4 months 2nd 1 month	ASD Epilepsy Tic Disorder NOS	Tourette Syndrome	8 years	Mother
TS009 16 years	10 years	Male	3 months Day patient 4 months	ASD ADHD		6 years	Mother
TS010 15 years	11 years	Female	5 months	MDD Panic Disorder		4 years	Mother

ADHD = attention deficit hyperactivity disorder; ASD = autism spectrum disorder; GAD = generalised anxiety disorder; MDD = major depressive disorder; NOS = not otherwise specified; OCD = obsessive-compulsive disorder; ODD = oppositional defiant disorder

3.3.2 Thematic analysis: themes and subthemes

The themes and subthemes identified in the study are summarised in Table 3.2. Overall, two main themes emerged. Theme One (“A turn in the road”) reflected the parent-child dyad’s perspective of inpatient admission as a catalyst for positive outcomes. Theme Two (“Still a rough journey”) reflected perspectives on ongoing difficulties after discharge.

Table 3.2 Themes and subthemes identified in the study

Theme 1: “A turn in the road”	Theme 2: “Still a rough journey”
Inpatient admission seen as the catalyst for positive outcomes	Ongoing difficulties after discharge from inpatient admission
Subtheme 1.1 Improved functioning after inpatient discharge, with knowledge of diagnosis	Subtheme 2.1 Minimal improvement of children lacking diagnosis
Subtheme 1.2 Improved functioning after inpatient discharge, when equipped with cognitive and behavioural skills	Subtheme 2.2 Lingering problems despite improvement
Subtheme 1.3 Change to appropriate school associated with positive outcomes	Subtheme 2.3 Regression associated with transition to mainstream secondary school
Subtheme 1.4 Development of relationships with peers related to positive outcomes	Subtheme 2.4 Lack of peer relationships associated with negative outcomes
Subtheme 1.5 Sustained progress associated with continuation of psychiatric follow-up care and medication	Subtheme 2.5 Negative outcomes associated with discontinuation of psychiatric follow-up care and medication
Subtheme 1.6 Improved relationships with parents after inpatient discharge, related to positive outcomes	

The majority of families experienced inpatient admission as positive and helpful, and reported positive outcomes, but with ongoing difficulties over time. Two main themes emerged from the 10 parent-child dyads as important factors related to the outcomes of the children after inpatient admission. Theme 1 highlighted factors related to positive outcomes, while theme 2 related to ongoing challenges and less positive outcomes. Diagnostic certainty, newly acquired cognitive and behavioural skills, improved parent-child relationships, appropriate school placements, development of peer relationships, as well as follow-up psychiatric care and medication, were seen as contributing to positive outcomes. Conversely, ongoing difficulties included lingering problems despite improvement, minimal improvement while lacking diagnosis, regression with transition to mainstream secondary school, negative outcomes associated with a lack of peer relationships and discontinuation of psychiatric care and medication. Below we provide further details including illustrative quotes.

3.3.2.1 Theme 1: “A turn in the road”. Inpatient admission seen as the catalyst for positive outcomes

3.3.2.1.1 Subtheme 1.1: Improved functioning after inpatient discharge, with knowledge of diagnosis

Families described that inpatient admission was instrumental in the diagnosis of their children. For example, parents revealed that two children (aged 10 and 14) were diagnosed with autism spectrum disorders (ASD), and the psychotic episodes of a child with ASD were found to be due to epilepsy. Diagnoses of Tourette Syndrome and obsessive-compulsive disorder (OCD) were made in another child after almost 3 years of outpatient treatment. Other inpatient diagnoses included depressive and anxiety disorders. Parents expressed how diagnosis led to fundamental positive change.

“I know a lot of people say don’t stick to diagnosis, but it made sense, and everything was so much easier after that” [Parent 006]

"It allowed me to understand exactly why I was there, and they helped me work through it"
[Child 006, Male]

"So this unit saved his life" [Parent 008]

"Probably the right medication [was the thing that helped]" [Child 008, Male]

3.3.2.1.2 Subtheme 1.2: Improved functioning after inpatient discharge, when equipped with cognitive and behavioural skills

All participant children felt that inpatient admission was beneficial to some extent. The majority learnt coping strategies and social skills. Despite a year of outpatient treatment, one child participant only managed a return to school after inpatient treatment (Child 010, Female). She gained confidence and learnt to manage her anxiety, while another (Child 003, Female) was helped when empowered to express herself constructively. This is evident in the following quotes:

"I won't say she was her confident old self that she was before she became anxious, but you could see she was more settled, more calm, she didn't get anxiety attacks anymore, because they taught her how to control it" [Parent 010]

"I went from this scared person, scared person that was drawing away from... in her own space, to being a person who was open and talked to everyone" [Child 010, Female]

"And I think if it wasn't for the admission... it would have been a very different outcome"
[Parent 006]

"The best part... being able to fold my clothes, just getting ready for bed, and easy, I think I enjoyed that. That gave me the time to realise okay this is what I'm doing, and this is how I can apply it to real life" [Child 006, Male]

3.3.2.1.3 Subtheme 1.3: Change to appropriate school associated with positive outcomes

All children were appreciative of change to an accommodating educational environment. The three who remained at an appropriate school (Child 003, Female; Child 006, Male; Child 010, Female), continued to succeed. The participant who changed to a school for autism (Child 008, Male), learnt cognitive and behavioural skills there, whilst his parent felt supported. Participants said:

“That changed his life 100%, because he would be very different now, I don’t think he would have finished school to be honest” [Parent 006]

“[going to an appropriate educational environment was] ... exactly same thing that I did here [in the inpatient unit], just a bigger scale” [Child 006, Male]

“[School for autism] is now our family, next year it’s [Child 008] and I, totally in the real world alone” [Parent 008]

“I probably wouldn’t be at the school I am now, and without that I probably wouldn’t have finished school in itself” [Child 008, Male]

3.3.2.1.4 Subtheme 1.4: Development of relationships with peers related to positive outcomes

Regardless of diagnosis, the development of friendships was associated with positive outcomes. Satisfaction with friendships was reported by all children with sustained improvement. This is indicated in the following comments:

“It gave him the ability to make friends outside” [Parent 009]

“Some of the best time I’ve ever had... making friends at my new school” [Child 009, Male]

“And he would always joke and say because everybody’s abnormal like him at [the appropriate educational environment]... so he became a different person” [Parent 006]

“Partying and stuff, I just never saw that. I always thought I’d be a book guy forever, and then next thing you know I was like, made friends” [Child 006, Male]

3.3.2.1.5 Subtheme 1.5: Sustained progress associated with continuation of psychiatric follow-up care and medication

All children with positive outcomes still attended outpatient follow-up and still required medication. Participants stated:

“Just for seeing her from where she was, and now where she is, I must say, it’s like a star shining in the sky” [Parent 003]

“It got much better. There’s still ups and downs, but not a lot” [Child 003, Female]

“It’s just thankfulness ... that’s how I feel when I walk in here” [Parent 010]

“I believe everyone has a point in time when they need help, and um, for me I have my mom, and I have God, and I have the doctors here that I see every 6 months” [Child 010, Female]

3.3.2.1.6 Subtheme 1.6: Improved relationships with parents after inpatient discharge, related to positive outcomes

Parents commented on the marked reduction of conflict at home. Two children (Child 003, Female; Child 010, Female) were enabled to communicate their concerns to parents and found this helpful. This is illustrated in the following quotations:

“We no longer had the constant fighting ... My home was a battlefield, it was like a warzone” [Parent 009]

“Helped with coping with emotions” [Child 009, Male]

“And she’ll tell me if something made her unhappy, which she never did” [Parent 010]

“Learnt to speak about difficulties and to voice opinion” [Child 010, Female]

3.3.2.2 Theme 2: “Still a rough journey”. Ongoing difficulties after discharge from inpatient admission.

3.3.2.2.1 Subtheme 2.1: Minimal improvement of children when diagnosis lacking

Participant parents claimed inpatient treatment was largely ineffective for the child who received subsequent diagnoses of ASD, OCD, generalised anxiety disorder (GAD) and major depressive disorder (MDD) (Child 002, Male); and the child discovered to be transgender (Child 004, Female). However, both children claimed it lowered their aggression. Participants reported:

“I got worse, he got worse, he wasn’t better when he came out” [Parent 002]

“Did help slightly with my behaviour and everything... my physical violence was lowered quite a bit” [Child 002, Male]

“So I wouldn’t say anything improved hugely” [Parent 004]

“I felt a lot better, I was definitely calmer” [Child 004, Male]

3.3.2.2.2 Subtheme 2.2: Lingering problems despite improvement

One participant (Child 001, Male) required additional medication and therapy in the medium-term outcome period, while four encountered setbacks in the long-term (Child 005, Male; Child 007, Female; Child 008, Male; Child 009, Male). Symptoms remained evident in participants with ASD (Child 008, Male; Child 009, Male), although no symptoms were mentioned for one participant (Child 006, Male). Participants commented:

“Anxiety has obviously remained a challenge” [Parent 008]

“And then just went up and down up and down, until now” [Child 008, Male]

“I thought it had been resolved... and there was nothing, the scars were fading and then I checked again and there she was cutting again” [Parent 007]

“There was a stage where I really felt overwhelmed, and I was harming myself, I don’t do that anymore though” [Child 007, Female]

3.3.2.2.3 Subtheme 2.3: Regression associated with transition to mainstream secondary school

A participant (Child 009, Male) who had received a diagnosis of ASD managed well in a new mainstream primary school, but not after the transition to secondary school. A participant (Child 007, Female) who flourished after starting in an inclusive class at a new primary school, needed to resume psychiatric treatment after transitioning to a mainstream secondary school. A third child (Child 005, Male) who changed secondary school and stopped having a private tutor and classroom, struggled to cope.

“Junior school was fantastic; High school crash and burn” [Parent 009]

“Uh, so I mean another teacher that was another clash of personality was my grade 8 and grade 9 math teacher... it made maths for me hard, which previously was actually quite easy...” [Child 009, Male]

“Um, she’s had some very traumatic things happen to her at the high school...” [Parent 007]

“I realised I had a lot more responsibilities, and a lot more work to do” [Child 007, Female]

3.3.2.2.4 Subtheme 2.4: Lack of peer relationships associated with negative outcomes

For all child participants with negative outcomes, a lack of friends was reported. Loss of peer relationships was evident for those who deteriorated with change of school. Participants expressed:

“He hasn’t made many friends, he finds it difficult to socialise” [Parent 005]

“I listen to music, but I’m not doing much else” [Child 005, Male]

“He still struggles. That’s part of his isolation at school, he’s totally isolated... he has his old friend back now” [Parent 002]

“I’ve changed so much. I don’t really relate to very many people” [Child 002, Male]

3.3.2.2.5 Subtheme 2.5: Negative outcomes associated with discontinuation of psychiatric follow-up care and medication

Poor outcome was associated with the two participants who discontinued post-discharge follow-up (Child 002, Male; Child 004, Male). Moreover, deterioration resulted in two 16-year-old participants refusing to continue follow-up care, although one child (Child 005, Male) continued taking medication. The other (Child 009, Male) had also discontinued school the previous year, which had followed his discontinuation of Ritalin (stimulant medication prescribed for ADHD) the year prior. Participants said:

“I took him out of school, because again, everything with him, was just falling to pieces”
[Parent 002]

“So it’s been still kind of bad... but I think now it’s okay” [Child 002, Male]

“When he went off Ritalin that’s when everything, he just crashed” [Parent 009]

“When you realise that you don’t know what you want to do with your life... and when you can’t find something, it sort of demotivates you, and I, at the moment I’m very demotivated”
[Child 009, Male]

3.4 Discussion

The study aimed to describe parental and child perspectives about their experience of inpatient psychiatric admission and outcomes after discharge from a preadolescent unit in Cape Town, South Africa. We used a qualitative methodology and semi-

structured in-depth interviews of ten parent-child dyads to establish (a) their experience of inpatient admission, (b) how they viewed their own short, medium, and long-term outcomes, and (c) what they perceived to be important factors that contributed to these outcomes. Our goal was to determine outcome variables of importance to families and service users that could be used in future outcomes-based research.

Overall, inpatient psychiatric admission was viewed as a strong contributor to positive outcomes by most parent-child dyads, summarised by the theme “a turn in the road”. and was associated with positive long-term outcomes by more than half of parent-child dyads. However, many families commented on ongoing challenges, as summarised by the theme “but still a rough journey”.

In many ways the findings of the qualitative study complemented results from the scoping review as presented in Chapter 2, but also identified new elements not previously reported in literature. Receiving an inpatient diagnosis was deemed life-changing by parent-child dyads, many of whom previously attended psychiatric outpatient services. Notably, a 13-year-old (Child 006, 6 years post-discharge) was diagnosed with ASD after 6 years of being a psychiatric outpatient. The subjective value of inpatient diagnoses was not highlighted by any of the studies in our review. Half of the participants described the helpfulness of the new intervention techniques they were taught (e.g. cognitive and behavioural techniques) and associated the skills development with positive outcomes. This is similar to findings from parent training programmes (Furlong et al., 2012). Parents remarked how these acquired skills resulted in an improved relationship with their child. Short-term studies that emphasised the inclusion of parents in therapeutic work, reported similar success (Gavidia-Payne et al., 2003; Ise et al., 2015). In our qualitative data, short-term improvements were not sustained in the medium-term account of the youngest (8-year-old) and most recently discharged participant (Child 001, 15 months post-discharge) with oppositional defiant disorder (ODD) and ADHD. The mother reported improvement both at home and with a facilitator at school. However, while continuing to have follow-up care, his behaviour deteriorated at school 11 months after inpatient discharge. This finding was very much in keeping with short to medium-term outcomes in the scoping review, where improvement was mostly found at five and six months post-discharge (Green et al., 2001; Mayes et al., 2001; Sourander & Leijala, 2002).

Most parent-child dyads recounted changes in the long-term outcome period, occurring two or four years after inpatient discharge. One participant (Child 008, 8 years post-discharge) needed inpatient readmission in his second year post-discharge. Thereafter, becoming a weekday border at his school for autism (which he commenced after his first inpatient admission), was deemed beneficial by both mother and child. The child mentioned having friends at the hostel, albeit they were younger than him. At the time of qualitative data collection, he was in his final year at the school, and described that he was experiencing frequent panic attacks. In line with this finding, an identified study in the scoping review (Green et al., 2007) found sustained improvement one year post-discharge, but negative changes in outcome within two years were reported in the earlier review by Blotcky and colleagues (1984). Only minor problems regarding the participant with depression and separation anxiety were relayed (Child 003, 2 years post-discharge), as well as another diagnosed with depression and panic disorder (Child 010, 4 years post-discharge). However, despite improvement, ongoing problems were found three years post-discharge in identified studies of the scoping review (Mattejat et al., 2001; Sourander & Leijala, 2002). None were reported in our qualitative data for the oldest participant (19 years old) diagnosed with ASD (Child 006, 6 years post-discharge), though he took medication for anxiety the year of data collection, after completion of secondary school. A further two parent-child dyads (Child 009, 6 years post-discharge; Child 007, 7 years post-discharge) described a largely positive outcome until entering mainstream secondary school two years prior to qualitative data collection. All the participants had changed to a more suitable educational environments soon after inpatient discharge, which was largely viewed as fundamental to their positive progress (Child 003, Female; Child 006, Male; Child 007, Female; Child 008, Male; Child 009, Male; Child 010, Female). Likewise, an identified 16-year outcome study in the scoping review (Healy & Fitzgerald, 2000) associated a change of school with positive outcomes. Participants spoke of making friends, while half had felt bullied at their previous school. This (bullying), as well as poor social integration, is commonly experienced by those having psychiatric difficulties (Knollmann, Knoll, Reissner, Metzelaars, & Hebebrand, 2010; Preyde et al., 2017). The child with MDD and panic disorder (Child 010, 4 years post-discharge) who only changed class, as well as the child with MDD and separation anxiety (Child 003, 2 years post-discharge), had refused school for a year prior to admission, substantiating the association of emotional disorder with school absence (Finning,

Ford, Moore, & Ukoumunne, 2020; Ogilvie et al., 2019). While poor peer relationships have been connected with psychopathology (de Graaf et al., 2018), an identified study (Green et al., 2007) in the scoping review highlighted that forming peer relationships while an inpatient was indicative of positive outcome. Self-esteem is increasingly gained outside the home, including from peer relationships and school, as children get older (Lewandowski et al., 2014). It was found to override all variables (besides less overprotection by depressed mothers), to significantly predict mental health in a 20 year follow-up study of children (Lewandowski et al., 2014). All participants who expressed satisfaction post-discharge had continued follow-up care. This is in line with an identified study (Fontanella, 2008) that associated aftercare with positive outcomes, as have most outcome studies (Blotcky et al., 1984; Kolko, 1992; Pfeiffer & Strzelecki, 1990; Trask & Fawley-King, 2016).

Of the children who regressed after a second school change, the child (Child 007, 7 years post-discharge) with a resumption of tics felt that she was recovering with renewed outpatient care (discharged the previous year). Another (Child 009, 6 years post-discharge) became disillusioned, refusing school and his usual follow-up care for a year prior to the qualitative data collection. He and his mother attributed his regression to teachers that were unaccommodating of his ASD diagnosis, in keeping with Preyde and colleagues (2017) reporting that conflict with teachers was commonly experienced by psychiatric inpatient youth. His mother also associated the decline with the discontinuation of his Ritalin medication the previous year, and stated that he had not made any friends at the secondary school. The anorexia nervosa of the third child (Child 005, 4 years post-discharge) had predictably largely improved, as illustrated in Chapter 2 by an identified study (Nilsson & Hägglöf, 2005). However, characteristically of anorexia nervosa patients, his father reported additional psychiatric difficulties (Mairs & Nicholls, 2016; Nilsson & Hägglöf, 2005) of social anxiety and recent depression, with refusal to continue attending outpatient care (although he continued the prescribed medication). The year prior to data collection, the child had moved to a larger mainstream school without his private tutor, as he appeared to have made a remarkable recovery while having a girlfriend.

Until recent gains, the participants who conveyed negligible improvement had discontinued follow-up care, though the mothers continued with their own therapy. Both mothers stated that they were unable to implement necessary changes, which is

indicative of the mental health problems they mentioned having themselves (Mattejat & Renschmidt, 2008). They described strained parent-child relationships, while an identified study Blader (2006b) in the scoping review established continual parenting stress typically predicts a poor prognosis. The participant with GAD and ASD (Child 004, 3 years post-discharge) who had been bullied prior to admission, felt relief moving to a home school. After revealing wanting to change gender a year before collection of the qualitative data, psychological care, as commonly required by gender-diverse people, commenced (de Graaf et al., 2018). Child and parent reported subsequent overall improvement, with the mother delighted by their improved relationship. However, the child was refusing school due to fear of stigma; which is commonly experienced by youth who have mental health difficulties (Kaushik, Kostaki, & Kyriakopoulos, 2016). The participant with ADHD (Child 002, 5 years post-discharge), was subsequently also diagnosed with ASD, OCD, MDE and GAD. He began attending a new school six months prior to qualitative data collection, having left school a year before following ongoing resistance to attend: a common attempt to mitigate mental health problems (Ogilvie et al., 2019). He subsequently resumed attending the psychiatric outpatient service, with good effect, according to the mother. Notably, both parents spoke of improvements in their own mental health that occurred prior to recent progress.

This qualitative study revealed that parent-child dyads highly valued the diagnostic certainty and skills obtained during inpatient admission. It also exposed factors seemingly necessary for positive long-term outcome. These largely mirror those identified necessary in a study of child and adolescent psychiatric inpatients: the support of family, friends, school staff and mental health professionals, including coaching in social skills (Preyde et al., 2017). Ignorance of CAMH problems is an obstacle to receiving professional help (V. Patel, C. Kieling, P. Maulik, & G. Divan, 2013). Our study highlighted the contribution that an applicable educational environment makes towards positive mental health outcomes, particularly as that was where participants made friends. In order to achieve in an educational environment, cognitive and behavioural engagement have been found necessary; however, feeling emotionally content there has been established to be just as important (Wang & Peck, 2013). Schools have been identified to be prime places to target CAMH programmes (Babatunde, van Rensburg, Bhana, & Petersen, 2019; Kern et al., 2017), which have

been found to increase community understanding and result in less school drop-outs. Preyde and colleagues (2017) reported that child and adolescent inpatients had 'overwhelming' concerns about engaging in the school environment while having mental health difficulties. Besides worrying about coping with the academic aspect of school, most feared social isolation, or loneliness. Comprehending and attending to these concerns is vital to helping these youths attain a positive trajectory into the future (Preyde et al., 2017).

3.5 Limitations of the study

We acknowledge that this qualitative study presented data from only ten parent-child dyads who had attended one preadolescent inpatient mental health unit in Cape Town, South Africa. We can therefore not presume that findings may be generalisable to other units in South Africa, Africa or internationally. However, to our knowledge, this is the first ever qualitative study to explore parent and child perspectives about outcomes related to inpatient mental health admissions. From this perspective, findings may at least stimulate further exploration of similar functional outcomes in other clinical settings and in future research. We further acknowledge that, apart from the small sample, follow-up periods were not very long for the majority. However, a strength of the study design was the parent-child dyadic data that provided complementary findings from both perspectives. As outlined in the methods, we recognise that qualitative analysis posed risks of biases. We have tried to increase trustworthiness of findings through the use of independent data collectors, and the inclusion of a senior, independent co-rater.

3.6 Conclusion

In this qualitative study of parent-child dyad perspectives about outcomes after inpatient mental health admission for preadolescents, the majority of families found inpatient admission positive and helpful, and indicated positive outcomes – but with ongoing difficulties over time. The 10 parent-child dyads identified diagnostic certainty, school placements, friendships and ongoing psychiatric follow-up as important factors contributing to outcomes. It is therefore noteworthy that parent and child perspectives

were much more focussed on functional outcomes (such as participation in school and community activities), than in measurable mental health/behavioural outcomes (as those typically used in outcome studies). In addition, an accommodating educational environment seemed to be a vital contributor to positive mental health outcomes of children and adolescents, particularly as an environment for the establishment and maintenance of friendships. The concerns expressed about the detrimental impact of mainstream secondary schools on the mental health of young people underline the importance of also considering mental health expertise, knowledge and interventions in schools, and not only in health-based contexts.

3.7 Chapter summary

Globally, inpatient admissions of preadolescents with mental health disorders are limited and relatively little is known about their outcomes. Findings from a recent scoping review identified a largely positive effect of inpatient admission on short-term outcomes, mixed medium-term outcomes, and unclear long-term outcomes. Many methodological challenges were identified, including absence of internationally agreed outcome measures. Where measures were used, they tended to focus on mental health/behavioural symptoms. This raised the question about what children and families who had experienced inpatient admission regarded as important factors related to outcomes. We therefore set out to describe the short, medium, and long-term outcomes of children after discharge from an inpatient unit in South Africa, from the perspectives of the children and their families. After appropriate ethical permissions were sought, potential study participants were identified from former inpatients at the preadolescent inpatient unit in Cape Town, South Africa. Perspectives of ten parent-child dyads were gathered using in-depth, individual interviews by an independent research assistant. Data generated from the interviews were transcribed and analysed using thematic analysis. To increase robustness of findings, 30% of all transcripts were double rated by a second, independent researcher with high-level expertise in qualitative analysis. Two main themes related to outcomes emerged from the 10 parent-child dyads included in the study. The first theme (*“A turn in the road”*) highlighted inpatient admission as the catalyst of positive outcome. Diagnostic certainty, newly acquired cognitive and behavioural skills, improved parent-child

relationships, appropriate school placements, development of peer relationships, as well as follow-up psychiatric care and medication, were seen as contributing to positive outcomes. Conversely, the second theme ("*Still a rough journey*") described ongoing difficulties, including lingering problems despite improvement, minimal improvement when diagnosis was lacking, regression with transition to mainstream secondary school, and negative outcomes associated with lack of peer relationships and discontinuation of psychiatric care and medication. Parent and child perspectives were focused on functional outcomes rather than on the mental health/behavioural symptom outcomes, typically used in outcomes research. Our results suggest a number of findings that might provide helpful pointers towards outcomes in clinical practice, and may suggest functional domains to consider in future outcomes research in child mental health.

Chapter 4

Integration of findings

4.1 Summary of the findings in the thesis

In this thesis we set out to investigate the outcomes of preadolescent children after inpatient admission for mental health disorders, both locally and internationally. In Chapter 1 we presented brief background information on child mental health and child inpatient psychiatry to contextualise the overall research questions in the thesis. In Chapter 2 we performed a scoping review to explore outcomes and follow-up after child psychiatric admissions based on all peer-reviewed data since the year 2000. In Chapter 3 we used a qualitative methodology to describe outcomes of children after discharge from an inpatient unit in Cape Town, South Africa, from the perspectives of the children and their families.

As outlined in Chapter 1, mental health problems represent the greatest burden of all health problems for people under the age of 18, and 50–75% of adult mental health disorders have their onset before the age of 18. A small number of under-18-year-olds are admitted to psychiatric inpatient units, and the majority of those are adolescents. Very little is therefore known about outcomes after inpatient admission in preadolescent children. A comprehensive review by Blanz & Schmidt in 2000 highlighted many difficulties with outcome studies. However, no reviews of outcomes after mental health inpatient admission of under-13-year-olds (referred to in the thesis as ‘children’ to differentiate them from ‘adolescents’) had been performed since the year 2000.

Our study employed a sequential exploratory design with two phases, to meet the two main aims of the project.

In the first phase (Chapter 2) we wanted to describe the current evidence-base or international landscape of short, medium, and long-term outcomes of children after discharge from inpatient psychiatric units. We did this by performing a scoping review

of existing international peer-reviewed literature since 2000, and identified a total of 17 studies that met inclusion criteria. We found that outcome data of child psychiatric inpatient treatment remained limited and conflicting, and were all from high-income countries (HICs). Improved psychological functioning was evident in short-term outcomes, while medium-term and long-term outcomes had mixed and unclear results, with marked deterioration in very long-term studies. Variable lengths of inpatient stay (ranging from 1 week to 1.7 years) and follow-up period (ranging from 4 weeks to 23 years), lack of comparable and standardised measures (where 59 measures were used across the 17 studies), absence of community comparison/contrast groups, and lack of comparison with other treatment modalities/settings contributed to the overall conclusion of the scoping review that there remains many gaps in the knowledge-base around outcomes after inpatient treatment of children with mental health disorders. It was particularly problematic that there were no widely used measurement instruments or consensus on key outcome variables that might have informed our own planned outcomes study in Cape Town, South Africa. We noted that no studies had sought parent and child perspectives about inpatient admission and follow-up after admission, which might have identified outcomes of particular importance to young people and their families.

We therefore decided to perform a qualitative second phase. In the qualitative phase (Chapter 3) we explored the perspectives of parent-child dyads relating to their experiences of inpatient admission and outcomes after discharge from a preadolescent psychiatric unit in Cape Town, South Africa. Perspectives about admission were very positive overall. Diagnostic certainty and newly acquired skills were recalled as valuable by most parent-child dyads. Participants reported improved parent-child relationships, with less conflict and better communication. Positive outcome was also thought to be influenced by psychiatric follow-up and having an appropriate educational environment where successful attendance and new friendships were formed. The thematic analysis also identified predictors of poor outcomes, which included children who lacked diagnosis, discontinuation of psychiatric follow-up and/or prescribed medications, and transition to mainstream secondary schools. Thematic data identified that, even though most children had positive short-term outcomes, the majority of them continued to experience difficulties, particularly in the medium to long-term.

Many of the qualitative findings mapped well onto the findings from the scoping review, including considerable short-term (1–4 months) improvement after inpatient admission, with newly acquired skills found to be beneficial (Gavidia-Payne et al., 2003; Ise et al., 2015). In addition, positive outcomes were largely retained one year after inpatient discharge, in line with findings from Green and colleagues (Green et al., 2007), but were reported as more mixed after three years, similar to data from Sourander and Leijala (2002). An important theme of relevance in clinical and research settings was the value and role of educational environments, either to support positive outcomes (when the environment was a good fit for the child, and positive peer relationships could be established and nurtured), or as a negative factor (when transition to an inappropriate secondary school may be associated with adverse outcomes) (Healy & Fitzgerald, 2000).

Taking together findings from our work, inpatient stay for child psychiatric patients was found to result in substantial short-term benefits to children and their families. These were associated with improved outcomes in mental health and behavioural symptoms, and in parent-child communication, educational success, and establishment of positive peer relationships. Over the medium and longer-term, outcomes became much more mixed, and were associated with health-related factors (e.g. ongoing psychiatric follow-up) and with educational factors (e.g. ongoing access to an appropriate educational environment and thoughtful transitions from primary to secondary education).

It was of great clinical value to hear the very positive views of parents and children about their inpatient experience. This was a reassuring finding, given the many financial and logistical challenges associated with inpatient treatment of young people, and the lack of quantitative outcome data in international and local literature. A particularly helpful finding from the qualitative data was the fact that parent-child dyads not only commented on reduction in symptoms and behaviour (the typical outcomes measured in literature), but also reflected on much more functional and personally meaningful outcomes, such as improved parent-child communication, acquisition of self-management skills, transition to an appropriate educational environment, and establishment of meaningful peer relationships. Our findings suggested that these may be equally important to consider for future measurement of outcomes, alongside the more easily quantifiable aspects typically reported in literature.

4.2 Limitations of the study

Despite the importance of outcomes, there have been very few studies of the short, medium, or long-term outcome of children admitted to inpatient psychiatric units. We therefore hope that this study will make a valuable contribution to the literature in this regard. We acknowledged a range of limitations in Chapters 2 and 3 as they related to the methodologies of the specific studies. Here we consider some wider limitations.

In Chapter 2 we acknowledged that data extraction for the scoping review was done only for the period 2000–2017, and that some significant additions to outcomes research may have been published since 2017. The 2017 cut-off was a pragmatic one on our part, and the challenges of the COVID-19 pandemic prevented us from updating findings further. A clear recommendation from our work is therefore the need for a follow-up or update of the scoping review performed in this study. However, we hope that the findings of both the scoping review and the qualitative study may help to shape future reviews on the topic.

We acknowledged in Chapter 3 the limitations associated with qualitative research and with the generalisation of findings from a small sample. However, as identified in the scoping review, there are very few contributions to the international literature from low- and middle-income countries (LMICs), and no qualitative contributions to outcomes research internationally. We therefore believe that this was a unique contribution of the work presented here. It would be of great interest to see further qualitative research also from other countries, including LMICs.

Both the scoping review and qualitative study were based on retrospective (or reflective) data. We acknowledge that the most robust outcomes evaluations should be set up and performed prospectively and this would be an important aim for future research. In the meantime, outcomes research based on retrospective/reflective data as used here, may still be of value, provided that all limitations and weaknesses are acknowledged.

4.3 Future directions in outcomes research

It is clear from this thesis that outcomes research in relation to child mental health inpatient treatment is an important yet highly under-investigated field of research. Our findings point towards a range of next steps that could strengthen outcomes research.

4.3.1 The need for international consensus on timeframes and outcome measures

Future outcomes research will require international consensus on timeframes for outcome studies. To date, the short, medium, and long-term groupings have been based on pragmatic clinical and research decisions, rather than on any longitudinal data. It may be that these will continue to be helpful timeframes, but it would add significantly to the international literature if these could at least be based on clear consensus.

As outlined in the scoping review, there is also clearly a need for international consensus on key variables for outcomes, identification of standardised outcome measures, and agreement on levels of outcomes to be explored. The Child Behavior Checklist (CBCL) and Children's Global Assessment Scale (CGAS) were the most frequently used in outcomes research over the study period. Both of these measurements were developed in the USA and have been widely used internationally (Deighton et al., 2014; Schorre & Vandvik, 2004). While there are more than 100 scales used in CAMH research, the cross-cultural validity of most is unknown (Stevanovic et al., 2017; Babatunde, van Rensburg, Bhana et al., 2021). Much further work is therefore required to reach consensus on measurements to use, and of constructs to be measured. We would propose that a process be set up to generate international consensus relevant to post-admission outcomes. There are global initiatives that have worked on generation of functional outcomes, e.g. the ICF projects to generate 'core sets' for ADHD and autism spectrum disorders (Bölte, Lawson, Marschik, & Girdler, 2021), and current initiatives to generate outcomes for various other neurodevelopmental and mental health disorders, e.g. ICHOM (<https://www.ichom.org>).

4.3.2 The need to include the voices of children and families in outcome measures

The qualitative findings in this thesis were a powerful reminder of the importance of including children and families in the process to identify appropriate and meaningful outcome measures. There is a global movement towards more participatory research (Cargo & Mercer, 2008; Jarg & Stefan, 2012) and towards ‘patient-reported outcome measures’ (Weldring & Smith, 2013). This may also be a very valuable step in CAMH outcomes research. The ICHOM initiative listed above, has a particular focus on ‘patient/self-reported’ outcomes, and the US Federal Drug Administration (FDA) also has targeted programmes to develop patient/self-reported outcome measures for clinical trials (<https://www.fda.gov/regulatory-information/search-fda-guidance-documents/patient-reported-outcome-measures-use-medical-product-development-support-labeling-claims>).

4.3.3 The need for more outcomes research in low- and middle-income countries

It was striking that the majority of outcomes research to date had been conducted in high-income countries. Given that the majority of children around the globe live in LMICs, it would be important to also include CAMH outcomes research from these culturally and linguistically diverse communities. It is possible that the socio-cultural and socio-economic contexts in LMICs may be associated with different priorities in relation to outcomes, and are certainly likely to be associated with many challenges in the selection, validation and cross-cultural use of measurement tools (Atilola, 2015; Babatunde et al., 2019; Lundh, Kowalski, Sundberg, Gumpert, & Landén, 2010; Stevanovic et al., 2017).

The need to include the voices of children and families is equally important in LMIC contexts. However, it comes with additional challenges. There is a great lack in public knowledge of mental health disorders in LMICs and very high levels of stigma, which makes it very difficult to include young people and their families in research around mental health (Zhou et al., 2020). Very deliberate efforts will therefore be required to reduce stigma, increase mental health literacy and knowledge, to increase research participation in LMICs.

4.3.4 The need for CAMH outcomes research in outpatient services

Whilst the work in this thesis focussed on outcomes after inpatient admission of children, the majority of child & adolescent psychiatry and mental health work is based in outpatient and community settings. The same efforts to study outcomes could be applied very powerfully in outpatient settings, and could provide very valuable information to clinical services, service managers, funders and policy-makers in future.

4.3.5 The need to also examine outcomes outside the health sector

As identified in our qualitative work, children and families think of outcomes not only in relation to health outcomes, but also in terms of educational and community participatory outcomes. It will therefore be important to ensure that future research on CAMH outcomes also include educational, social, and participatory outcomes. To ensure this, stakeholders from these sectors (education, social development, non-profit, civil society, etc.) should also be included as active participants in future CAMH outcomes research.

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Appendix A: Interview Schedule of Questions

Interview Schedule of Questions

a. Interview questions for parent/guardian of a previous TLC patient

1. When your child was a patient at the TLC, what do you feel changed for the better or worse?
2. After your child was discharged from the TLC, what do you feel changed for the better or worse?
3. What helped or hindered after discharge?
4. Tell us about your experience of the TLC?
5. Do you have any specific memories of the TLC that you could share with me?

b. Interview questions for adult previous patient

1. When you were at the TLC, what do you feel changed for the better or worse?
2. After leaving the TLC, what do you feel changed for the better or worse?
3. What helped or hindered you after discharge?
4. Tell us about your experience of the TLC?
5. Do you have any specific memories of the TLC that you could share with me?

c. Interview questions for child previous patient

1. When you were at the TLC, what things got better or worse for you?
2. After leaving the TLC, what things got better or worse for you?
3. What helped or made things difficult for you after leaving the TLC ?
4. What was it like to be at the TLC?
5. Are there some things that you remember about the TLC that you could tell me about?

Appendix B: Demographic Questionnaire

Questionnaire

Demographic Data of Child

I AM A

Previous TLC patient.	Parent / Carer
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Age of myself/ my child	
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Gender of myself /my child	Male		Female	
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Home Language	English		Afrikaans		isiXhosa		Other	
---------------	---------	--	-----------	--	----------	--	-------	--

Education	Yes	No
I / my child completed Primary School Grade 7		
I / my child completed High School Grade 12		
I / my child completed studies after school		
If Yes, what qualifications did you / your child obtain:		

I / my child live with	One parent	
	Both parents	
	Relatives	
	In a Children's Home	
	Alone	
	With a partner	

I am / my child is	Single	
	Married	
	Divorced	
	Widowed	
	Have a child	
	If Yes, how many children?	

	Yes	No
Is there conflict at home?		
Is there financial problems?		

Psychiatric Health	Yes	No
I am / my child is currently receiving psychiatric / psychological care by a healthcare professional		
I have /my child has received psychiatric / psychological care by a healthcare professional after discharge from the TLC (Therapeutic Learning Centre)		
If Yes, for how long? Where and by whom did I receive treatment after discharge?		
I have / my child has been an inpatient at a psychiatric hospital after discharge from the TLC		
If Yes, how many times:		

Have I / has your child received any psychiatric diagnoses?

If Yes, what are they?

Medical / Physical Health	Yes	No
I am /my child is in good health		
If No, mention why?		

This form has been completed by	Mother	
	Father	
	Relative	
	Caregiver	
	Yourself	

Participant No.

DATE

Appendix C: Information Sheet

Information Sheet

I, Tania Swart, am a Masters student in Psychiatry at the University of Cape Town (UCT). From August 2004 until the end of 2017, I worked at the Therapeutic Learning Centre (TLC); which is the Psychiatric ward of Red Cross War Memorial Children's Hospital.

The aim of this study is to learn about the outcomes of children after discharge from the psychiatric unit (TLC), of Red Cross Children's Hospital. I am inviting all patients who were at the TLC between 2009 and 2016 and their guardians, to be involved in this study. It will take place during 2018. Patients or their guardians (if they are unable to participate), will be required to answer questionnaires that should take about half an hour to complete. This will take place in a private room of the psychiatric unit, or any other safe place in Cape Town that is preferred by you. The questions will be in English.

Your/your child's responses will be kept confidential; this means that your/his or her name will not be with the answers. Instead, your/his or her questionnaire will be allocated/given a number; so that you/he or she will not be identified. Only researchers will have (access to) your responses. The questionnaires and audiotapes will be kept for ten years after the study, and will then be destroyed.

You/your child might not benefit/gain anything directly from participating/taking part, but your/your child's involvement will inform us how children manage after they are discharged from an inpatient psychiatric facility. This information can be reported to healthcare providers and the families of these children, to try to better understand and help them. You/your child will be given one hundred rand for your/his or her involvement in this study. If you have any expenses (such as transportation costs) due to your/your child's participation, this will be reimbursed.

Your participation/taking part in this study is voluntary/because you/your child want to, and you/your child may withdraw/stop at any point if you/he or she so wish. There will be no consequence regarding your/his or her choices, and you/your child will receive your/his or her normal service at any clinic you/he or she attend at Red Cross Children's Hospital or elsewhere. Your/your child's decision to participate/take part or not, will be respected.

You will be asked to rate how you/your child manage daily activities, and how you/your child feel and behave in different situations. You/your child will fill in the forms by yourself/him or herself, but the researcher will be available to help you/him or her.

You may also be asked to participate in an interview. It will take about half an hour and will be audio-recorded. You will be asked how you/your child experienced/found the TLC. Also what changed (concerning you/your child) when at the TLC and afterwards.

If you/your child choose/s to participate/take part, you/he or she may choose not to answer a specific question. You/he or she may also ask questions during and after the study, to help you/him or her understand. If you/he or she become worried or confused during the study, please let me know; and I shall help you as best I can. If you want further information, you may contact:

Professor Petrus J. de Vries. Division of Child and Adolescent Psychiatry (DCAP), University of Cape Town. Telephone: + 27 (0) 21 6854103; Fax: +27 (0) 21 6891343.

This study has been approved by the University of Cape Town and the Health Research Ethics Committee (HREC). The HREC is a committee that ensures that participants in the study are not harmed, and that their rights are respected. The UCT Faculty of Health Science (FHS) Human Research Committee can be contacted on: + 27 (0) 21 406 6338, if you have any queries concerning your rights and welfare as a research subject on the study.

Appendix D: Consent Form

I _____ (name), have read the information sheet or listened to it being read to me. I have had the opportunity to ask questions, and these have been answered satisfactorily. I understand the information about the study, and voluntarily consent to participate in this study.

I am also aware , as outlined in the information sheet, that the following types of questions will be asked:

Where and by whom did I receive treatment after discharge from the TLC?

Overall, do you think that you have difficulties in any of the following areas: emotions, concentration, behaviour or being able to get along with other people?

Do the difficulties upset or distress you?

Name of participant: _____

Signature of participant: _____

Date: _____

Name of researcher: _____

Signature of researcher: _____

Date: _____

Appendix E: Assent Form

Even though your mom or dad gave permission, you still have a choice to take part or not.

I _____ (name) by putting my name at the bottom, have read the information sheet or listened to it being read to me. I have been able to ask questions, and these have been answered satisfactorily. I understand it well and freely agree to be part of the study.

I also know, as the information sheet says, that the kind of questions I shall be asked will be like these:

Where and by whom did I receive treatment after discharge from the TLC?

Overall, do you think that you have difficulties in any of the following areas: emotions, concentration, behaviour or being able to get along with other people?

Do the difficulties upset or distress you?

Name of participant: _____

Signature of participant: _____

Date: _____

Name of researcher: _____

Signature of researcher: _____

Date: _____

Appendix F: Ethical Approval UCT



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: sumayah.arietdien@uct.ac.za

Website: www.health.uct.ac.za/fhs/research/humanethics/forms

06 November 2018

HREC REF: 585/2018

Prof P de Vries

Division of Child & Adolescent Psychiatry
46 Sawkins Road, Rondebosch

Dear Prof de Vries

PROJECT TITLE: OUTCOMES OF PRE-ADOLESCENT CHILDREN AFTER IN-PATIENT PSYCHIATRIC ADMISSION MSc Candidate - Ms Tanla Swart)

Thank you for your response letter addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 November 2019.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student: Ms Tanla Swart will also be involved in this study.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies

Appendix G: Ethical Approval Red Cross War Memorial Children's Hospital



DR AN PARBHOO
Manager: Medical Services
Red Cross War Memorial Children's Hospital
Email: Anita.Parbhoo@westerncape.gov.za
Tel: +27 21 658 5430 Fax: +27 21 658 5006/5166

28 December 2018

Ms T Swart
Division of Child & Adolescent Psychiatry
UCT

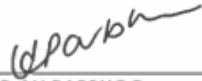
Dear Ms Swart,

RESEARCH: RXH: RCC 169

PROJECT TITLE: Outcomes of Children after Inpatient Psychiatric Admission

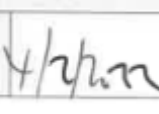
It is a pleasure to inform you that the hospital Research Review Committee has approved your application to conduct above-mentioned study at Red Cross War Memorial Children's Hospital.

Yours sincerely,



DR AN PARBHOO
MANAGER: MEDICAL SERVICES

Appendix H: Ethical Approval UCT 2022

	UNIVERSITY OF CAPE TOWN UNIBESITHO YASEMANTH - UNIVERSITEIT VAN KAAPSTAD	HUMAN RESEARCH ETHICS COMMITTEE - 2 FEB 2022 FACULTY OF HEALTH SCIENCES Human Research Ethics Committee HEALTH SCIENCES FACULTY UNIVERSITY OF CAPE TOWN	
FHS016: Annual Progress Report / Renewal			
HREC office use only (FWA00001637; IRB00001938) This serves as notification of annual approval, including any documentation described below.			
☒ Approved		Annual progress report	
☐ Not approved		See attached comments	
Signature Chairperson of the HREC		Date Signed	
			
Comments to PI from the HREC			
Principal Investigator to complete the following: 1. Protocol information			
Date (when submitting this form)		26 January 2022	
HREC REF Number		585/2018	
		Current Ethics Approval was granted until	
		30/01/2022	
Protocol title		Outcomes of pre-adolescent children after inpatient psychiatric admission	
Protocol number (if applicable)		N/A	
Are there any sub-studies linked to this study?		☐ Yes ☒ No	
If yes, could you please provide the HREC Ref's for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.			
Principal Investigator		Prof Petrus J de Vries	
Department / Office Internal Mail Address		Division of Child & Adolescent Psychiatry, 46 Sawkins Road, Rondebosch, 7700	