Psychiatric Inpatient Care for Children and Adolescents: Consumer Perspectives

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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>TABLE OF CONTENTS</td>
<td>2</td>
</tr>
<tr>
<td>List of Figures and Tables</td>
<td>7</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>8</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>9</td>
</tr>
<tr>
<td>STATEMENT OF THE ORIGINALITY OF THE WORK</td>
<td>12</td>
</tr>
<tr>
<td>PREAMBLE</td>
<td>13</td>
</tr>
<tr>
<td>CHAPTER 1- INTRODUCTION</td>
<td>14</td>
</tr>
<tr>
<td>Thesis Overview</td>
<td>14</td>
</tr>
<tr>
<td>Introductory Background</td>
<td>15</td>
</tr>
<tr>
<td>Mental Health Services in Australia</td>
<td>16</td>
</tr>
<tr>
<td>Models of Care</td>
<td>18</td>
</tr>
<tr>
<td>Hospitalisation</td>
<td>19</td>
</tr>
<tr>
<td>Who is the Consumer?</td>
<td>27</td>
</tr>
<tr>
<td>Consumer Satisfaction</td>
<td>31</td>
</tr>
<tr>
<td>Existing Research</td>
<td>35</td>
</tr>
<tr>
<td>The inpatient unit</td>
<td>39</td>
</tr>
<tr>
<td>Contributions</td>
<td>40</td>
</tr>
<tr>
<td>Research Approach</td>
<td>40</td>
</tr>
<tr>
<td>Academic and Scientific Rigour</td>
<td>43</td>
</tr>
<tr>
<td>Credibility</td>
<td>44</td>
</tr>
<tr>
<td>Transferability</td>
<td>44</td>
</tr>
<tr>
<td>Dependability</td>
<td>45</td>
</tr>
<tr>
<td>Confirmability</td>
<td>46</td>
</tr>
<tr>
<td>Ethical Considerations</td>
<td>46</td>
</tr>
</tbody>
</table>
Summary of Findings ................................................................. 170
Significance of Findings ............................................................. 176
Implication of the Findings ......................................................... 177
  Changes in service delivery ................................................. 178
  Education around the role of the various services ................. 179
Contribution of the Findings ..................................................... 181
Methodological Strengths ......................................................... 182
Methodological Limitations ....................................................... 183
REFERENCES .......................................................................... 185
APPENDICES ........................................................................... 214
APPENDIX 1: Information Sheets and Consent Forms ................. 215
  APPENDIX 1.1: Information Sheet: Referrer ........................... 215
  APPENDIX 1.2: Consent Form: Referrer ............................... 217
  APPENDIX 1.3: Information Sheet: Minor ......................... 219
  APPENDIX 1.4: Consent Form: Minor ................................. 222
  APPENDIX 1.5: Consent Form: Legal Guardian/Parent .......... 224
  APPENDIX 1.6: Information Sheet: Adolescent ................. 226
  APPENDIX 1.7: Consent Form: Adolescent ......................... 229
  APPENDIX 1.8: Information Sheet: Adult ......................... 231
  APPENDIX 1.9: Consent Form: Adult .............................. 234

APPENDIX 2: Paper 3: I don’t want to be here but I feel safe: Referral and admission to a child and adolescent psychiatric inpatient unit; The young person’s perspective .................................................. 236
Appendix 3: Paper 4: In this day and age why is it still so hard to find the right type of help? Carers’ perspectives around child and adolescent mental health services: A qualitative study

245
List of Figures and Tables

Figure 1: Flowchart of study selection ................................................................. 59

Table 1: Search strategy terms by database ......................................................... 60

Table 2: Results of Quality Assessment for Quantitative Studies (Based on JBI MASTARI Checklist Criteria) ................................................................. 63

Table 3: Results of Quality Assessment for Qualitative Studies (Based on JBI MASTARI Checklist Criteria) ................................................................. 75

TABLE 4: Studies of Consumer Satisfaction with Child and adolescent mental health services ................................................................................................. 87
“It takes a village to raise a child”.

Ancient African Proverb

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Abstract

Very little published research exists describing the lived experiences of referring clinicians, young people, and parents/carers of young people accessing psychiatric inpatient care. The aim of this qualitative research project is to gain a clearer understanding of the referral process and admission experience from the perspective of the three consumer groups. Identifying similarities and differences between the groups, as well as aspects of experiences with mental health services which were most or least satisfying, may identify consumer specific needs that can in turn, influence continuity in care and contribute to improved mental health.

Thirty-one participants comprising nine mental health clinicians, eleven patients of the inpatient unit and eleven parents/carers of young people admitted to the inpatient unit, participated in interviews that lasted between 15 to 109 minutes. The interviews were analysed thematically following the guidelines of Braun and Clarke (2006; 2013). Measures to preserve qualitative rigour were employed from the initial stages of the process, until the writing of the results.

Four areas based on the research aims were chosen as a focus for the thesis. Each was the subject of a separate paper: a) a systematic review of the literature on satisfaction around child and adolescent inpatient mental health services, specifically inpatient care; b) the experiences of referrers to the inpatient unit; c) the experiences of young people admitted to the inpatient unit; and d) the experiences of the parents/carers of young people admitted to the inpatient unit.

A systematic review of the literature (Paper One) demonstrated the very limited amount of published research focussing primarily on child and adolescent psychiatric inpatient care. The seven quantitative and seven qualitative studies that met the criteria for inclusion (based on Joanna Briggs Institute (JBI)
guidelines) demonstrated inconsistencies in methodology and design. They included different sample populations, treatment settings, population characteristics, and measures of outcome. This made generalizability of results difficult to achieve. The review highlighted the need for additional, methodologically rigorous research in this underreported area.

Referrers’ experiences with referral to and admission of young people in their care to the inpatient unit (Paper Two) identified “safety and risk management” as the overall theme and driving force behind referral to the inpatient unit. The study highlighted the need for inpatient and community-based mental health clinicians to look towards innovative and collaborative service delivery in order to maintain the safety and well being of young people under their care.

The experience of young people with mental health services, including referral and admission to the inpatient unit (Paper Three) identified satisfaction as being influenced by a perceived connection with staff and to other patients on the ward. Furthermore, the ability of nursing staff to facilitate feelings of safety, security and acceptance contributed to the young person’s desire to remain engaged in treatment post-discharge.

To complete the range of user perspectives, Paper Four described the perceptions of carers of young people admitted to the inpatient unit. Carers were universal in their belief that the inpatient unit was the right place for their child. This was on the background of unsatisfactory experiences with community-based care that they perceived as of poorer quality and insufficient to meet their needs. With lack of confidence in community-based services, carers sought treatment post-discharge to be undertaken by the inpatient unit and staff.
The findings presented in this thesis may be valuable in the development of strategies for responding to mental illness, particularly in high-risk case scenarios. Increased education, flexibility in service delivery, and greater collaboration between inpatient and community-based services, has the potential to enhance the continuity and consistency in care that mental health services strive to achieve.
Statement of Originality of the Work

I, Gigetta Maria Luigia Salamone-Voli certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

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___ Gigetta ML Salamone-Voli.

Date: 15/11/16
Preamble

This thesis is formatted as a ‘thesis by publication’ comprising four articles, an Introduction and a Conclusion that draws the work together. Two of the articles presented as Chapters 2 and 3 of this thesis are unpublished and currently unsubmitted work written in manuscript style and appear as ‘text in manuscript’. Chapters 4 and 5 of this thesis represent two published articles. All articles are representative of the study undertaken towards this doctoral thesis.

The University of Adelaide Graduate Centre defines a “publication format” thesis as “an alternative to the conventional written thesis… that comprises a portfolio of publications which have been published and/or submitted for publication and/or comprise unpublished and un-submitted work written in manuscript style”. For further information please see www.adelaide.edu.au/graduatecentre/handbook/07-thesis/02-publication-format-thesis/
CHAPTER 1: INTRODUCTION

Thesis Overview

The guiding principle of this thesis is to contend that efforts in trying to understand what is of importance to consumers of child and adolescent mental health services, particularly inpatient care, may yield important answers regarding willingness to access care, participate in treatment, and strive toward better mental health. Therefore, the overarching purpose of this thesis is to generate an understanding of the experiences of three consumer groups (referring clinicians, young people as well as parents/carers of young people receiving mental health care), in identifying those aspects of care perceived as satisfactory or not, and/or requiring modification or change.

The thesis commences with an introduction to mental illness in young people living in Australia in the 21st century. Consideration of the literature on each of the three consumer groups regarding mental health services and accessibility is included. This will be followed by a description of the context of the role of the child and adolescent psychiatric in-patient unit and the pivotal role it plays in receiving, assessing, treating and referring on children and young people post discharge.

The introduction concludes with; a methodological account highlighting the need for a more thorough systematic review of the literature focusing on satisfaction in child and adolescent inpatient care, the aims of the project and research questions, the rationale behind research applying a qualitative approach with methodological rigour, and a statement on reflexivity. The subsequent four chapters consist of self-contained articles (published or prepared for publication/manuscript style) arising from the research. A conclusion ties
together the findings of all four papers and includes an evaluation of the implications and significance of the findings, their contributions to the field of study, and suggestions for future research.

**Introductory Background**

The majority of children and young people living in Australia have good mental health with positive psychosocial development and the capacity for effective learning. Good mental health is often associated with the presence of protective factors such as intelligence and good problem solving abilities (Perkins & Jones, 2004). Additional factors include a supportive peer group, strong family ties, religiosity, and involvement in sport clubs and other extra curriculum activities (Perkins & Jones, 2004). The absence of protective factors however, can lead a vulnerable young person into poor mental health.

Mental health disorders are becoming increasingly prevalent amongst young people (Wright, Jorm, & Mackinnon, 2011) with data published by the Australian Bureau of Statistics (2007) revealing that during a 12-month period, up to 14% of Australian children and adolescents aged 4-17 experienced some form of mental health or behavioural problems. The Centre for Parenting and Research, New South Wales Department of Community Services, in their literature review: “Effective Strategies and Interventions for Adolescents in a Child Protection Context” (2009), reported that all risk factors for developing mental illness could be found across five domains. These domains include: The “individual” domain (e.g., personality variables and developmental delays); the “family” domain (e.g., low socioeconomic status, mental illness, family conflict, and coercive parenting); the “peer” domain (e.g., peer rejection and deviant peer-group membership); the “school” domain, (e.g., academic failure, low
commitment to school); and the “community” domain (e.g., neighbourhood and poverty) (p. 7).

Whilst risk factors have been identified as contributing to a young person developing mental illness, mental illness itself has also been found to have strong links with poor self-esteem, school problems and difficulties, relationship formation, and poor academic and career attainment. Furthermore, the overall damage to the quality of life that results affects not only the young person, but also their families.

Evidence suggests that early and appropriate intervention can assist children and young people overcome or manage their mental illness and prevent it becoming a chronic condition leading to ongoing disadvantage and disability (Raphael, 2000). Early intervention however, can only be as effective as the young person’s desire to seek out and remain in treatment. It is also only possible if pathways to receiving care are straightforward and appropriate.

**Mental Health Services in Australia**

In Australia, government funded, non-government (NGO) as well as private organizations and services offering specialised mental health assistance to young people in need are available. The private sector in particular can be an expensive option however, whilst the public sector is prone to long waiting lists to access services. Introduced in 2001, the Australian Government-Funded Access to Allied Psychological Services (ATAPS) program was developed in order to improve access to mental health services for young people. ATAPS enables general practitioners or the family doctor (predominantly) to refer patients with high prevalence disorders for free or low-cost, evidence-based mental health care (for up to 12 sessions in one financial year) (Bassilios et al.,
2010). Since instigation, ATAPS has been independently reviewed and found to have high uptake (in terms of referral) in both urban and rural areas (Bassilios et al., 2010; Morley et al., 2007).

**Determinants and barriers to mental health help seeking.**

Assuming that an appropriate and effective referral pathway is in place does not guarantee that young people in need of mental health assistance will actively pursue services offered (Rickwood & Braithwaite, 1994). The 2007 Australian National Survey of Mental Health and Wellbeing, found that young people are less likely than other age groups to seek professional help. One study found that only 31 per cent of young women and 13 per cent of young men with mental health problems had sought any professional help (Slade et al., 2009). This leaves a potential group of young people at risk of ongoing mental health problems that if left untreated or inadequately treated, may result in deterioration warranting more intensive intervention including hospitalisation.

The decision to seek help is influenced by a number of factors (Rickwood, Dean, & Wilson, 2007). These factors include; recognition that the problem is one that requires help, preparedness to seek help or at least encouragement to do so, knowledge of how to access the help, and accessibility to assistance/help. The level of severity of the problem may also influence the decision to take up the referral, with young people themselves sometimes perceiving their problems as not serious enough to request care (Fenger, Mortensen, Poulsen, & Lau, 2011). Other factors which may prevent a young person seeking help for their mental illness include; being of ethnic minority, being of lower socio-economic status (Barker, Olukoya, & Aggleton, 2005), and having poor past experiences with mental health services, including perceived negative attitudes of staff towards the
young person, as well as issues around confidentiality, stigma, and trust (Breland et al., 2014).

Experiences of significant adults in the young person's life also have the potential to influence the decision around seeking treatment. Parental and/or caregiver characteristics influence mental health usage among young people, particularly if the parent/carer themselves has had experience with mental health services as a client (Burnett-Ziegler & Lyons, 2010). A negative experience is likely to result in reluctance to seek and remain in treatment. Embarrassment and concerns about their child being labelled or receiving a diagnosis, being judged a poor parent or having their child removed from the family should they seek help, have been identified as barriers to carers seeking help (Sayal et al., 2010). Financial difficulties, transportation issues and the actual location and environment where services are offered, have also been identified as possible barriers (Basilios et al., 2010; Rickwood et al., 2007).

Models of Care

The mental health needs of children and adolescents are "more closely related to the concepts of healthy social and emotional development than adult mental health" (Miles, Espiritu, Horen, Sebian, & Waetzig, 2010, p.21). The Australian Infant, Child, Adolescent and Family Mental Health Association (AICAFMHA), suggest that services that are offered should take into consideration the developmental framework relevant to the young person's specific needs (AICAFMHA, 2010). As children and adolescents' well-being is influenced by many systems including (but not exclusively), family and education, as well as welfare and community services (Raphael, 2000), when providing care to young people the aim of mental health practitioners is to
wherever possible, work alongside the support structures already in place and in their absence advocate for them on behalf of the young person.

The model of care proposed by the state government in which this study was undertaken, as part of their Mental Health and Well Being Policy (2010-2015), also promotes advocating for the mental well-being of young people, removing barriers to young people accessing and receiving care, working in collaboration with all service providers, consumers and carers, and ensuring that programmes offered meet the developmental as well as individual therapeutic needs of the young person.

**Hospitalisation**

Australian policy, similar to that in other countries around the world, focuses on treatment being provided in the least restrictive environment (Janssens, Hayen, Walraven, Leys, & Deboutte, 2013; Sheppard et al., 2009). The expectation is that the family and community services will provide the necessary support (Clinton, Lunney, Edwards, Weir, & Barr, 1998; Kent & Yellowlees, 1994; Shepperd et al., 2009), with hospitalisation recommended for severe mental health disorders that cannot be treated effectively through community-based care (Raphael, 2000).

In the Australian state in which this study was conducted, when hospitalisation is considered, the young person, their carer, and professional clinicians (GP, private psychiatrist, psychologist, other government and non-government organizations), can refer/self-refer for further assessment to the emergency department of the hospital in which the child and adolescent psychiatric inpatient unit is located. General practitioners, psychiatrists and community-based mental health services can also make direct referrals to the
inpatient unit, after consultation with the inpatient chief psychiatrist in determining suitability for admission, or identifying a more relevant/alternative service.

Young people presenting to the emergency department of the hospital are reviewed by the specialised triage service. The decision to admit or be referred to another more appropriate community-based service is made after an extensive assessment, which may include all or a combination of the following; a medical examination to ensure medical stability of the young person and eliminate the presence of an underlying medical condition contributing to the presentation, a thorough risk assessment including suicidal ideation and self-harm, a full mental state examination including developmental history, past psychiatric history and previous access to mental health services (including number and frequency of presentations to the emergency department), as well as determination of the level of supports already in place and accessible to the young person.

Clinical presentation alone will not determine admission to the inpatient unit. Similar to findings of the literature review by Janssens et al. (2013), the constraints of the mental health service delivery system often determine the outcome of the assessment process undertaken for admission. Since hospitalisation is considered the tertiary entry point for people experiencing mental health issues, it is arguably the more severe or complex presentations that result in hospitalisation. This means that the mental health issues are likely to be occurring in a background of severe behavioural or emotional disturbances that cause major disability and are associated with high risk of harm to self and/or to others (Mathai & Bourne, 2009). Those conditions are likely to include psychosis and other severe disorders of depression or anxiety, as well as a range
of conditions with co morbidity (Mathai & Bourne, 2009). However, there are occasions where psychosocial aspects of living with mental illness contribute to the decision to admit to an inpatient unit. Availability of alternative resources and the family’s capacity to care for the young person, both influences whether the young person is admitted, and for how long that admission may be (Janssens et al., 2013).

Accommodation issues, or reluctance of the carer/parent to accept the decision of the assessing clinician that admission is not warranted, may result in admission, particularly the case in overnight/after-hours presentation where the ability to locate alternative accommodation options is restricted. This case scenario is often interpreted by admitting inpatient units, including the unit in this study, as least desirable whilst acknowledging at the same time that family, carers and the young person themselves, require support and consideration. In the absence of alternative resources available to this group of participants, the inpatient unit fulfils the role.

**Voluntary vs involuntary admission.**

The aim of adolescent inpatient treatment is to reduce risk and severity of possible long-term psychopathology. The provision of intensive and multifaceted assessment and a therapeutic and contained environment facilitates this process (Gill, Butler, & Pistrang, 2016; Hanssen-Bauer, 2011). In most western democracies, individuals can have some input into whether or not they receive psychiatric care. However, in certain circumstances, particularly in the case of need for treatment and where there exists potential for danger towards self and/or other people, individual wishes can be over-ridden (Kaltiala-Heino, 2010). This is the same for child and adolescent as well as adult populations. This form of
intervention, although considered necessary at the time, may have resulted in a less than satisfactory experience.

Adult patients treated without informed consent may experience events that they consider humiliating and that may as a consequence, contribute to further harm and trauma (Kogstad, 2009). The use of restraint that can often occur with involuntary treatment, the perceived abuse of power and non-consideration of the person’s feelings or desires leading to a perceived loss of dignity, all contribute to a potentially negative experience, not only for the patient but for the treating team as well (Gustafsson, Wigerblad, & Lindwall, 2013). For adolescents in psychiatric care, this violation of autonomy may lead to a young person not getting better, or deteriorating further, or could result in an unwillingness to pursue treatment if required again at a later stage (Kaltiala-Heino, 2010). Whenever and wherever possible therefore, hospitalisation if it is required, ideally will occur on a voluntary basis.

**Changing nature of psychiatric legislation and length of stay.**

Over the last 30 years, psychiatric in-patient treatment has evolved from extensive, long term therapy, to brief treatment with the focus on crisis stabilization, assessment and discharge planning (Hopkins, Loeb, & Fick, 2009; Moses, 2010). These changes have contributed towards hospital lengths of stay becoming perceptibly shorter.

In the United States, the lengths of stay of youth receiving psychiatric services have decreased, not only to honour the legal principle of providing care within the least restrictive environment, but also influenced by the financial cost of such treatment (Stellwagen & Kerig, 2010). In Western European countries, there is now an increased tendency for case-based funding. Such case-based
systems provide a strong incentive to shorten length of stay. Each additional treatment day for diagnoses not covered for, or “reimbursed” at a lesser rate, is less profitable for the hospital (Warnke, Rossler, Nordt, & Herwig, 2014). In Australia, case-mix funding also applies to mental health, although no evidence has been found through a search of the literature suggesting a direct link between case-mix funding and length of stay.

In addition to service-based financial incentive, how long an individual remains in hospital is determined by a number of factors occurring in combination or alone (Jimenez, Lam, Marot, & Delgado, 2004; Zhang, Harvey, & Andrew, 2011). Of the studies that have addressed this issue, the findings are best summarised by the early study of Barber, Allen, and Coyne (1992). They identified three basic domains for which the basis of admission and length of stay are determined. They include; the patient domain (sex, age, diagnosis and symptoms, the young person’s strengths and or vulnerabilities, and the course and severity of psychopathology), the treatment domain (including proposed treatment/interventions during the hospitalisation, as well as plans for post hospital treatment), and the environmental domain (including type and degree of social support available to the young person and their family, stressors, family resources and liabilities).

An Italian study undertaken by Gigantesco et al. (2009) found that the ‘status’ of the hospital admission (private or public) influenced length of stay, with individuals in private care facilities experiencing a longer length of stay than those admitted to public health facilities. These findings were reflective of an adult population and comparisons with children and adolescents may not yield a similar result.
Research around public sector care for children and adolescents with mental illness found that ‘longer stays’ were associated with diagnoses of psychoses (Hallak, Crippa, Vansan, & Zuardi, 2003; Livingston, Taylor, & Crawford, 1990; Pavkov, George, & Czapkowicz, 1997), and ‘shorter stays’ with adjustment disorders, axis II diagnoses, cognitive impairment and substance use disorder comorbidity (Barber et al., 1992; Compton, Craw, & Rudisch, 2006). The increased use of psychotropic medications to treat conditions has also been found to result in shorter lengths of stay (Meagher, Rajan, Wyshak, & Goldstein, 2013). Family strengths and resources were associated with short or intermediate term treatment (Abas, Vanderpyl, Le Prou, & Crampton, 2006), and family psychopathology was most frequently noted in association with long-term treatment (Barber et al., 1992).

Concerns around the negative impact of prolonged or frequent long-term hospitalisation on the psychosocial functioning of patients admitted to psychiatric care, has been raised by parents of young children (Swadi & Bobier, 2005). (Concerns are that in-patient admission exposes their child to learning additional or new maladaptive behaviours). This has led many parents/carers of children with mental health problems to prefer treatment that can bring about improvement or stabilization in as short a time as practicable (Delaney & Engels-Scianna, 1996; Scharer, 2002).

**Length of stay and readmission.**

Recovery from mental illness is achieved on an individual basis, with some individuals requiring longer and others shorter episodes of care. Furthermore, some individuals may never require inpatient admission for their
condition, or only experience one acute episode, whilst others will require rehospitalisation on a subsequent occasion post initial discharge.

Symptoms present in adolescents experiencing brief psychiatric in-patient episodes may show sufficient improvement by discharge (Mayes, Calhoun, Krecko, Vessell, & Hu, 2001; Segal, King, & Naylor, 1995). According to American studies however, (Blanz & Schmidt, 2000) the shift in focus toward diagnosis and acute crisis stabilization through shorter inpatient admissions, has led to a “revolving door” pattern of hospitalisation for some individuals, to which Brinkmeyer, Eyberg, Nguyen, and Adams (2004) attributed increases in parent dissatisfaction with in-patient services.

In Australia, unplanned readmission rates have been identified as a Key Performance Indicator (KPI) with the underlying assumption that unplanned admissions to an inpatient psychiatric facility following a recent discharge (within 30 days post discharge), may indicate either incomplete or ineffective treatment, or that follow-up care was not adequately planned or utilised. This potentially points to deficiencies in the functioning of the overall care system (Key Performance Indicators for Australian Public Mental Health Services: Technical Specification Summary, 2008).

The assumption, however, that incomplete treatment may be a consequence of a shortened length of stay and may lead to readmission rates, is not consistently supported in the literature. Swadi and Bobier (2005) report that although there are limited published reports on effects of length of stay in child and adolescent populations, the available evidence suggests a similar trend to that identified in the adult population, that is, that longer hospitalisation does not necessarily decrease readmission rates nor does it necessarily improve social
adjustment. Fontanella, Pottick, Warner, and Campo (2010) in their study on discharge planning and the effects of medication management on readmission rates among adolescents in the USA, reported that the risk of rehospitalisation was higher for patients who had medication added to their existing medication regime, were placed in group homes, or discharged to a partial hospitalisation program, regardless of time spent in hospital. James et al. (2010) also found that psychiatric rehospitalisation among children and youth was highest within 30 days of discharge and remained elevated for up to three months post discharge. Furthermore, individuals experiencing their first hospitalisation were likely to experience early readmission if the length of stay was in fact longer, if they also had a higher risk assessment score on admission, and if they did not attend their post discharge follow-up. These findings suggest that length of stay alone for a child in treatment may not be directly related to readmission rates. Other factors such as protective factors and appropriate discharge planning and post discharge follow-up attendance may be more influential.

These results also suggest and perhaps not surprisingly, that the more complex presentations or those with biomedical and psychosocial difficulties are likely to experience readmission. At any one time, a decline in functioning may occur in an area not evident or targeted for treatment in a previous admission. In the case of first presentations, just as in outpatient appointments, an individual may need more than one episode of care before stabilization can be achieved. A number of short stay unplanned readmissions may not be an indication of treatment failure, but a better option than prolonged, singular admissions that come with their own set of concerns.
Who is the ‘Consumer’?

When admission to an inpatient unit occurs, there is an expectation that intervention offered will benefit the ‘consumer’ receiving that care. An individual with mental illness, who accesses a service for treatment of their mental illness, is an identified consumer of that service. Stallard (1996) suggests that the definition of consumers can include those who have utilised services in the past, as well as individuals likely to utilise services in the future. According to Mental Health Services Australia (Australian Institute of Health and Welfare, 2012), the term consumer includes individuals seeking help for others with mental illness. For the purpose of this thesis therefore, the term consumer has been expanded to include all relevant/significant others involved in the treatment of the young person who has experienced an inpatient admission at the time of the study. The referring mental health clinician, who is accessing the inpatient unit in order to provide assistance in the care of the young person experiencing mental health issues, can arguably be considered both a health provider and ‘consumer’. The young person seeking treatment and their parent/carer or guardian is also representative of those individuals considered ‘consumer’. All viewpoints around care received directly or indirectly are arguably equally important. This however, has not always been the case.

The referring clinician.

How the different consumer groups view satisfaction with mental health services may vary. Of importance but rarely discussed, are the perspectives of the referring mental health clinician/team around referral and admission of the young people in their care to the inpatient unit. Shipley, Hilborn, Hansell, Tyrer, and Tyrer (2000) state that satisfaction reported by referrers often does not
correlate with patients’ views. Referrer expectations may differ again from what the inpatient unit perceives their role to be. Rodrigo, Foo, and Majoor (2013) suggest that referrers are more satisfied and likely to refer again to services that are easily accessible with low waiting times, and provide interventions that are perceived as being relevant and of adequate duration. If the referring team perceives admission to be a difficult process, or if admission leads to disagreement or lack of clarification about decisions made during the admission and discharge, then referrer expectations are likely to be unfulfilled and satisfaction levels most likely compromised. This may impact on future referral patterns and/or involvement in patient care. The referring party’s perspectives and insights are therefore of importance.

**Adolescent rights in decisions around treatment.**

The first contact with mental health services can influence not only the outcome of the initial presentation but also the level of engagement the young person and significant others display beyond the time of initial contact or hospitalisation (Clarke & Winsor, 2010). Admission to an in-patient unit may be an extremely emotional experience for all concerned. That experience can be even more detrimental to an individual if they believe their autonomy, right to be heard and active participation in decisions around their care have been denied or compromised.

“People with mental health problems and mental illness have rights and responsibilities to be informed about and involved in decisions about their own individual treatment. They also have the right to contribute to the formulation of mental health legislation and policy, and to the design, implementation and evaluation of mental health services at national,
state/territory and local levels to ensure that services comprehensively meet their needs, including from a cultural perspective” (National Mental Health Policy, 2008, p. 12).

In the early days of child and adolescent mental health services, young people were considered incapable of judging what services might be good for them. More recently, adolescents’ rights to make decisions about their treatment and whom they wish to involve in that treatment, have been acknowledged (Martin, Petr, & Kapp, 2003). The opinions of young people are now paramount in decisions regarding overall treatment plans.

**Rights of the parent/carer.**

Family and carers of children with mental illness experience a wide range of emotions and difficulties that impact on their ability to provide and or seek out support for their children. Experiences around guilt, loss and grief, as well as physical exhaustion have been reported (Mohr & Regan-Kubinski, 2001). A child with mental illness has also been found to exacerbate tension within families (Delaney & Engels-Scianna, 1996). Stigma, real or imagined is also often of concern for families (Hilenge, Beale, & McMaster, 2006; Pejler, 2001; Sayal et al., 2010). Admission of their child is another stress point, with parents and carers identifying feelings of anxiety around how their child will be treated as an inpatient (Askey et al., 2009). Practical and emotional support (Pinfield et al., 2005) is therefore sought, along with affirmation and collaboration with treatment decisions around the care of their child (Jakobsen & Severinsson, 2006; Scharer, 2002; Tarico, Benson, Trupin, & Forsyth-Stephens, 1989). These needs however are not always met.
As the parent/carer is often an integral part of the treatment process for their child, satisfying the needs of the family should also become a major goal of treatment (Rey, Plapp, & Simpson, 1999). Every effort is required in ensuring that the young people receiving care, as well as their family/carer, are involved in all aspects of treatment decision-making. This level of involvement is in keeping with consumer rights and is a process advocated by the Australian government, through their mental health policies.

“Carers require acknowledgement and respect for the role they play. To perform their role effectively, carers must be able to access relevant information and services, whenever necessary. Carers also need to be able to access information regarding the treatment, on-going care and rehabilitation of the person for whom they are caring.” (National Mental Health Policy, 2008, p. 21).

The need to include carers in service delivery is extremely important in the light of evidence which suggests that the relationship the parent or carer establishes with the treating team can affect treatment outcomes (Scharer, 2000). Studies that examine parental satisfaction with mental health service delivery for children and adolescents conclude, “satisfaction of the relatives can be related to positive clinical prognosis” (Tas, Guvenir, & Cevrim, 2010, p. 770). Studies have also indicated that low satisfaction of the parent can affect treatment compliance and therefore overall treatment outcome (Gigantesco et al., 2002). This is the case for both inpatient and community-based treatment.
Role of consumer in service delivery and evaluation.

The referring clinician, children and adolescents receiving care, as well as their parent/carer, each have a role to play in mental health service delivery and evaluation. Donabedian (1992) specified three major roles the consumer may play in treatment evaluation. First, by defining and evaluating quality through the information consumers provide, the consumer takes on the role of ‘contributor’. Second, the consumers’ behaviours can be influenced or changed through education or addressing the circumstances that may have prevented them from acting in their own best interests. This identifies them as potential ‘targets’. Third, by being more pro-active and direct in consumer-practitioner exchange, the consumer can also be extremely influential through political lobbying. This role can be identified as a ‘reformer’.

When the consumer is an active participator in treatment delivery, then the likelihood of them accessing the service and return if required is increased. In order to ensure that this occurs, methods must be put in place to determine whether or not this involvement and satisfaction with involvement, is being achieved. Understanding consumer satisfaction is paramount in the design and development of mental health services.

Consumer Satisfaction

A review of the literature identified decades long attempts at defining consumer satisfaction. Oliver (1979, as cited in Stallard, 1996) claimed that satisfaction could best be understood by examining the amount of discrepancy between expectations and experience. Fox and Storms (1981) developed this with their ‘discrepancy and transgression theory,’ suggesting that if patients’ healthcare orientations and provider conditions were congruent, then satisfaction
results. Linder-Pelz (1982) expectancy-value theory suggests that an individual’s prior beliefs and values about care, in addition to prior expectations, can determine satisfaction. According to Lebow (1982), measures of consumer satisfaction assess “the extent to which treatment gratifies the wants, wishes and desires of clients” (p. 244). Ware, Snyder, Wright, and Davies’ (1983) determinants and components theory, argued satisfaction was a function of subjective responses to experienced care, mediated by personal preferences and expectations, whilst Brestan, Jacobs, Rayfield, and Eybert (1999) claim, “Consumer satisfaction in the context of psychosocial treatments refers to the extent to which patients or clients liked the process and the outcome of the treatment they received, including the treatment format, the techniques used, and the effects of treatment” (p. 18). Hopkins, Loeb, and Fick (2009) also claimed that in order to ensure that satisfaction has been achieved, the “degree to which initial expectations are being met” (p. 927) is important.

Consumer expectations appear an important component in all of the theories around consumer satisfaction; however, expectations are often based on past experience, or possibly even lack of it. Therefore, in those individuals with no or limited experience of mental health services, particularly for children and adolescents, expectations may be low and satisfaction reported high. It may also be that no prior exposure or understanding of the mental health system may result in unreasonable or unattainable expectations, and thus result in low satisfaction (Canter, 1989). Expectations alone therefore, may not be true indicators of satisfaction but merely one aspect of it.
Can satisfaction be measured?

Questionnaires have become the most popular method of gathering information around perceptions of care. According to Hawthorne (2006), although thousands of questionnaires have been developed, none of the instruments could be considered satisfactory. The most common criticism is that questionnaires have been developed on an “ad hoc” basis (Corrigan, 1990). Researchers have expressed concerns about the psychometric properties of survey questions, in particular multicollinearity, social desirability, response bias and validity (Fitzpatrick & Hopkins, 1983; Greenfield & Attiksson, 1989).

According to Riley, Stromberg and Clark (2005), global and multidimensional scales lack response variation and therefore often do not identify the less than satisfied user. The artefact of scale design, rather than a true perception of user satisfaction, is often the explanation behind high rates of reported satisfaction (Kaufman & Phillips, 2000).

An additional criticism is the emphasis on clinical perspectives when measuring quality of care. Very few instruments in the past have been designed to gather perspectives from the patient themselves, on other aspects of service delivery. This omission of consumer perceived values leads to low content and face validity (Kaufman & Phillips, 2000). Furthermore, studies have rarely considered previous research and have not included the same rating scales, symptom checklist or interview process. As a consequence, generalization of results can rarely be achieved.

Gill and White (2009) state that in addition to little standardization, low reliability and questionable validity of instruments used to measure satisfaction, concerns have been raised around ‘patient satisfaction’ and perceived ‘service
quality’ being used interchangeably. In reality the two concepts may not be related at all or bear limited relevance to each other. This is a belief shared by Biering (2010) who stated that the concept of consumer satisfaction is still underdeveloped and that few valid instruments have been developed to measure it. Consequently, results from research are often varied and inconsistent.

**Consumer satisfaction: A key outcome worth measuring.**

Regardless of the inconsistencies and difficulties in measuring satisfaction, the process of capturing what satisfaction means or entails for consumer groups in particular, is essential in ensuring that services are appropriate, accessible and successful in achieving recovery, progress in mental health and overall wellbeing.

"Mental health and other services should be geared to achieving positive outcomes for individuals and their families. These outcomes might be defined in different ways, and could include reductions in symptomatology and improvements in quality of life, as well as positive perceptions of care” (National Mental Health Policy 2008, p. 24).

**Benefits of qualitative research in identifying satisfaction.**

The use of questionnaires and surveys is not the only means of understanding satisfaction around services offered from the perspective of the consumer. Qualitative studies implementing focus groups and semi-structured interviews have also been employed in order to capture the experience of the mental health in-patient admission (Jones et al., 2009). Qualitative studies provide in depth information about the inpatient experience that can be used to both evaluate a service, identifying its strengths and weaknesses from different perspectives, as well as to influence future service type and delivery (Alvarez Del Arco, Rodriguez, Sanchidrian De Blas, Alejos, & Pia Mestre, 2012). Qualitative
measures allow the researcher to understand the experience of in-patient admissions through the perspective of the consumer. Most importantly, qualitative methods that employ semi-structured and open-ended interviews and questions, reduce researcher bias and allow greater focus on what the consumer views as relevant (Shenton, 2004).

**Existing Research**

Experiences with mental health services should be used to guide efforts in enhancing quality of care and service delivery. Until very recently however, published research on patient satisfaction with inpatient care for children and adolescents has been limited.

The most recent literature review was that of Biering (2010), who undertook an electronic search of the three literature data bases (PubMed, Medline and PsychInfo) from 1994-2007 and found 24 studies relating to the perceptions of young people receiving psychiatric care. Only three quantitative (Grossoehme & Gerbetz, 2004; Kaplan et al., 2001; Marriage et al., 2001) and four qualitative studies (Geanellos, 2000, 2002; Hart et al., 2005; Lee et al., 2006) focussed on inpatient care. Each of the papers was reviewed according to the research methods employed, research settings (outpatient, inpatient, mixed), purpose of the research and research findings. Biering’s (2010) analysis of the results from the 24 studies reviewed, suggested only weak-to-moderate correlation between a child and their parent’s satisfaction with mental health services. Ensuring that the experiences and perceptions of care for children are understood separate from those of their parents is therefore essential. In Biering’s (2010) review of the literature, parental satisfaction was found more likely related to “their assessment of functional improvement in their children
and/or their perception of treatment benefits” (Biering, 2010, p. 70). For adolescents however, satisfaction with mental health services was found to have three main domains: “satisfaction with the environment and organisation of the services; satisfaction with the adolescent-caregiver relationship; and satisfaction with treatment outcome” (p. 67). These findings are supported by the two earlier literature reviews undertaken by Garland et al. (2000) and Attride-Stirling (2003).

**Limitations.**

Biering’s (2010) review of the literature failed to provide information on the method applied in assessing the quality of the studies in the review and under reported or lacked information regarding the population characteristics of the studies, the length and duration of treatment, types of intervention, methods of data collection or analysis of the results. However, limitations in the methodologies applied in the studies reviewed by Biering (2010) were identified. For example, in the quantitative studies of which only three pertained to inpatient care, Biering (2010) suggested that the instruments designed to capture information solely on the three domains relating to child satisfaction around psychiatric care, lacked sensitivity around other measures of satisfaction, and that instruments that can measure different levels of satisfaction are more useful in ensuring better quality of care. He argued that instruments should also be developed to capture the different developmental stages as well as treatment settings in which the services have been provided. The qualitative studies reviewed by Biering (2010) however, were noteworthy in their ability to capture the young person’s experiences around care from their unique perspective. Future methodologically stringent studies utilizing a qualitative approach may prove more useful in yielding information from the perspective of consumers of mental
health services that is rich in description and transferable to other contexts and sites.

**Updated systematic review of the literature needed.**

On completion of the qualitative studies undertaken separately with all three consumer groups: referring clinicians (Chapter 3); young people admitted to a psychiatric inpatient unit (Chapter 4); and parents/carers of young people admitted to a psychiatric inpatient unit (Chapter 5), the author then undertook a systematic literature review that examined all available literature (including qualitative and quantitative studies) related to satisfaction with child and adolescent mental health care. The aim was to provide a current and relevant literature review, which can guide future research endeavours. This systematic literature review provides information from published research beyond that which appears in Biering's (2010) review and is a comprehensive evaluation of the methods and findings of identified studies on satisfaction with child and adolescent mental health services, particularly inpatient care. Consequently one of the studies undertaken as part of this thesis having met the inclusion criteria is included in the review which appears as ‘text in manuscript’ in Chapter 2 in this thesis.

**Rationale/Purpose of the Present Research Project**

The purpose of this research is to gain a clearer understanding of the process of accessing mental health services, including inpatient admission, from the perspective (perceptions and lived experiences) of referring community-based mental health clinicians, children and adolescents, as well as parents/carers of children and adolescents. The research project has four broad aims including:
1. To understand through existing literature and the course of this study, what events or circumstances lead to the referral and/or admission of a child/adolescent to a psychiatric inpatient unit.

2. To provide an account of how the mental health providers view the purpose of the in-patient unit.

3. To provide an account of how children and young people with mental illness interpret and make sense of their experiences.

4. To provide an account of the parents/carers of young children with mental illness, beliefs and perceptions around mental health services, including the in-patient admission.

As evidenced through the most recent review of the literature (Biering, 2010), very little published research exists that explores the entire experience of accessing, utilising and evaluating the mental health services from the perspective of the three main consumer groups. This study aims to qualitatively explore the following questions:

- How do consumers from different groups experience and respond to the available mental health services for children and young people?
- What are the differences and similarities between referring clinicians, children and young people and parents/carers around their experiences?
- What aspects of the experiences with mental health services including referral, admission and discharge from inpatient unit, were most and/or least satisfying?
The inpatient unit.

The inpatient unit, from which participants were drawn, is a designated psychiatric inpatient facility for children and adolescents up to the age of 18 in one state in Australia and provides specialised care and support for children and adolescents with severe mental health problems. The range of mental health problems young people admitted to the inpatient unit experience include early stages of psychosis, severe mental disorders including depression and anxiety, often with suicidal component, and complex and co-existing disorders that require multiple assessments and specialised care. The inpatient unit currently provides services for children and adolescents under a variety of legal orders. The unit operates as an open ward. Young people not under an involuntary treatment order (ITO) are able, after consultation with the ward staff and with permission from their parents if under 16 years of age, to leave and enter the ward voluntarily. Closed facilities for young people (within or separate from the rest of the ward) are not provided. Children and adolescents who present a risk to themselves or others under the Mental Health Act are managed within the open unit and may at times require additional one-to-one nursing care for all or part of the admission episode. For additional security, the ward doors can be locked when there is a perceived increased possibility of a young person at risk absconding.

The inpatient unit averages over 500 admission episodes per year, with a mean average length of stay of 5-6 days. Those with severe psychiatric disorders, such as psychosis, have a length of stay above the average mean, whilst those admitted in crisis or with an adjustment disorder, often experience a length of stay below the average.
Contributions.

This project aims to make a valuable contribution to the existing, but limited body of literature, on perceptions of satisfaction of in-patient admission for children and young people suffering mental illness, from the perspective of the three main consumer groups (referring mental health clinician, child or adolescent, as well as parent/carer of a child/adolescent admitted to a psychiatric inpatient unit). Research of this description with this population group and in this setting has not been carried out anywhere else in Australia. Referring mental health clinicians may have different expectations to those of young children admitted to the inpatient unit and different once again, from the parent/carer themselves. The desired outcome of the admission may also be perceived differently amongst the three participant groups. Understanding what is of importance to all consumer groups who access mental health services is therefore instrumental in designing a relevant and appropriate service aimed at improving quality of care and enhancing overall mental health.

Research Approach

Several researchers have argued that the research questions and the phenomenon under investigation should determine the methodology to use (Creswell, 2007; Mays & Pope, 1995; Silverman, 2005). Critical psychologists have questioned whether experiences of illness are amenable to quantitative measurement, experimental manipulation and statistical analysis. Crossley (2007) reports that such approaches have often failed to provide rich and ‘true’ representations of human experiences. Information gained from such measures often group individuals into categories or types without offering explanation or understanding of the experiences and expectations which lead an individual to think, react or behave in a particular manner.
Qualitative research is a common methodological approach in the area of health research (Holloway, 1997). Through the use of observation and interviews, the phenomenon under study can be understood in the context of the culture, or the setting in which it is placed. For example, the use of qualitative methods in health-related research has contributed to insight into health professionals' perceptions of consumer participation in care and have identified barriers to changing healthcare practice (Al-Busaidi, 2008).

Phenomenology is one of the research approaches used in qualitative research. Phenomenology was inaugurated by Edmund Husserl in the very beginning of the 20th Century (Zahavi, 2003). According to Creswell (2007), "...a phenomenological study describes the meaning for several individuals of their lived experiences of a concept or a phenomenon" (pp. 57-58). The phenomenon under study may include a culture, a program or, as in this thesis, an organisation. The phenomenological design aims to obtain "comprehensive descriptions that provide the basis for a reflective structural analysis that portray the essences of the experience" (Moustakas, 1994, p. 13). In order to achieve this, selecting qualitative samples requires a focus on a collection of participants who provide specific narratives to clarify and deepen the exploration of the study (Neuman, 2003). A purposeful sampling method in which the particular research locations and participants are selected by the researcher, increases the probability that they will be able to provide the information necessary to address research questions.

The phenomenological approach provides a rich and complete description of human experiences and meanings. Without a pre-set hypothesis or other researcher-based expectations, findings emerge rather than being imposed by an
investigator. A qualitative design was chosen for this project therefore, to gain understanding of the lived experience of the participants, as well as the meanings the participants placed on their experiences with accessing and receiving mental health services.

Individual interviews with participants, was the process of data collection applied in the studies. The use of open-ended questions allowed each participant the opportunity to speak freely on issues of interest and of relevance to them.

In order to make sense of interview-based findings, thematic analysis has been applied following the guidelines of Braun and Clarke (2006; 2013). This method of analysis organises, compares and finds patterns in the data that has been generated, in this case, from interviews conducted with three separate groups of participants. Braun and Clarke (2006; 2013) have identified 6 stages in thematic analysis described as: 1) data familiarisation; 2) code generation; 3) theme identification; 4) theme review; 5) defining and naming of themes; and 6) report production. The stages do not follow a linear pattern. Each stage is revisited as the analysis progresses and themes are refined and renamed.

Thematic analysis was chosen for this research because unlike other forms of data analysis, it is not reliant on specific theories and disciplines in order to carry out the research. Instead, the results obtained, whilst offering complexities of meaning can be utilised in a meaningful manner across disciplines (Boyatzis, 1998).

Triangulation of results gathered from each of the consumer groups included in this study provided an opportunity to gather a rich, robust and comprehensive understanding of consumer experience with psychiatric inpatient care. Triangulation has been viewed as a qualitative research strategy to test
validity through the convergence of information gathered from different sources (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014).

The procedures used for recruitment of participants, data collection and data analysis, are located in each of the papers in the subsequent chapters. Sample size for each of the consumer groups under study was determined through the process of constant comparison, until data reached ‘saturation’. In qualitative research, saturation is taken to indicate that sufficient data have been collected “for a comprehensive and credible analysis to be conducted” (Kerr, Nixon, & Wild, 2014, p. 271). Sample size varies among studies, with saturation reached with smaller numbers in some studies and requiring additional numbers for others. Guest, Bunce, & Johnson (2006) noted that data saturation may be attained by as little as six interviews. Whilst there are no formal standard tests for estimating or proving an adequate sample size for reaching saturation (Kerr, Nixon, & Wild, 2014), researchers agree on the following principles; no new data, no new themes and no new coding (Fusch & Ness, 2015). In this study, an audit trail was kept during data collection and data analysis to determine when saturation was reached, that is, the point at which collected data are repetitive and are not providing new information (Morse, 1995).

**Academic and Scientific Rigour**

Enhancing trustworthiness and controlling for bias that may impact on the findings of the research undertaken, is part of the process towards ensuring quality and rigour in qualitative research. Lincoln and Guba (1985) were one of the first to ask the question of how qualitative researchers could persuade audiences that the findings of their studies were worth paying attention to. Tracey (2010) is a more recent source and both shall be discussed below.
Lincoln and Guba (1985) proposed criteria including; credibility, transferability, dependability and confirmability, as essential in order to ensure quality of the qualitative research. These criteria will be discussed below in the context of the research undertaken in this thesis.

**Credibility: What is the extent in which participant accounts are faithful to their responses?**

Participant validation or ‘member checking’ is a technique used in qualitative research for rigour and trustworthiness in the context of the credibility of the results (Birt, Scott, Cavers, Campbell, & Walter, 2016). In this thesis, participant validation was sought prior to the data being analysed. Participants were provided an opportunity to make changes or inclusions and give other feedback on the completeness of their interview transcripts. However, it should be noted that this type of validation can only confirm the results to be an accurate representation of participants’ lived experience at the time and place of interview.

Only 6 of the 31 participants requested a review of the transcripts, with two making modifications, one to include additional information and the second to make grammatical changes in order to improve readability of the document. However, no assumption can be made around those participants who did not request a review. For example, it cannot be concluded that participants were not in agreement with the contents of their transcripts.

**Transferability: Can the results of the study be applied to, or are considered useful in other settings?**

According to Lincoln and Guba (1985) by describing a phenomenon in sufficient detail, the researcher can begin to evaluate the extent to which the conclusions drawn are transferable (to other people, settings, situations, and
time). Shenton (2004) states, "without this insight [thick description] it is
difficult for the reader of the final account to determine the extent to which the
overall findings "ring true" (p. 69). As was the case in each of the studies in this
thesis, by providing detailed information of the research process including
methodology and context of the study (nature of the psychiatric inpatient unit,
participant characteristics including inclusion and exclusion criteria, data
collection and analysis and reporting of the results) other researchers are able to
replicate the study using similar conditions in other contexts/sites. The individual
interviews and use of participant quotes provided rich information about personal
experiences and perspectives. The information gathered from the three consumer
groups accessing psychiatric inpatient care for children and adolescents as well as
the method applied in gathering that information, expands potential for relevance
across other similar settings.

**Dependability.**

In this study the process of peer reviewing by the academic journal peer
review process was the means by which the criterion of dependability was
measured. Peer reviews allow others external to the study, to review and
understand the process used by the researcher and determine its reliability in
being able to be replicated or recreated across settings. The paper on the young
persons' perspective has been published in the International Journal of Mental
Health Nursing (see Chapter 4). The paper on the carers' perspective (Chapter 5)
has been published online in the Journal, Advances in Mental Health. The papers
on the systematic review of the literature (Chapter 2), as well as the paper on the
referrers' perspective (Chapter 3) are unpublished and currently unsubmitted
work prepared in manuscript style.
Confirmability.

This refers to the quality of the results produced by the researcher in terms of how well they are supported by participants’ actual responses. The PhD candidate coded an initial interview that was then checked and verified by the two supervisors in order to achieve coding agreement. In addition, an audit trail was kept containing raw data, reflections, reactions, analytical ideas, throughout each aspect of the data collection and analysis. The material in the audit trail, and the checking of codes by supervisors, helps to ensure that the data and interpretations made by the PhD candidate in this study (inquirer) are internally coherent, and represent more than “figments of the [inquirer’s] imagination” (Guba & Lincoln, 1989, p. 243).

Since Lincoln and Guba (1985), others have offered insight about best practice in qualitative research. According to Tracey (2010), high quality qualitative methodological research is marked by: (a) worthy topic; (b) rich rigour; (c) sincerity; (d) credibility; (e) resonance; (f) significant contribution; (g) ethics; and (h) meaningful coherence. These criteria produce research that can be considered self-reflective, conscientious and thorough. The researcher’s adherence to ethical principles, reflective practice and transparency are considered below.

Ethical Considerations

This research addressed the relevant requirements aimed at guarding the safety of all participants, according to the principles of the NHMRC “National Statement on Ethical Conduct on Human Research” (NHMRC, 2007). Confidentiality, privacy and anonymity were assured for all participants in the study. Participants through informed consent (Appendix 1.2; 1.4; 1.7, & 1.9)
were granted full knowledge of what the study entailed, the aims as well as the objectives of the research and were given the right to withdraw from the study at any time (Appendix 1; 1.3; 1.6, & 1.8). They were also informed of their right to interrupt or terminate the interview process if they wished to do so. None of the participants withdrew from the study or terminated interview sessions prior to completion.

Transcriptions of interview recordings, along with signed consent forms have been electronically saved on disc and are stored at the University of Adelaide for seven years (from the commencement of the research). The audit trail along with paper copies of the interviews and consent forms are stored at the hospital in which this study was undertaken for 30 years. Each participant was given the opportunity to request a copy of his or her transcribed interview. Six participants requested a review, in order to check and or delete information or improve readability of the information provided during the interviews (participant validation). All potentially identifying information was removed from the written text.

A protocol for addressing any psychological or other distress experienced by participants as a consequence of the interview was devised between the PhD candidate and her supervisors. Before exiting the interview room, the interviewer ensured that the participant was not distressed as a consequence of any of the discussions or information shared. In the event that this was the case, an opportunity would be provided for participants to discuss the matter further with appropriate personnel (in this instance, either by contact with the supervisors, ethics board member or the psychiatrist on the inpatient unit). The interviewer would facilitate this discussion. However, no participants reported distress.
Reflexivity in Theory

In qualitative analysis, “meanings are made, not found” (Mauthner & Doucet, 2003, p. 414). That is, the role of the researcher is to interpret participants’ accounts and experiences and to be transparent about their role and position within the research context. In order to achieve this, researchers often provide reflexive accounts that contribute to the quality of the research process, rigour and credibility (Jootun, McGhee, & Marland, 2009).

According to Marshall and Rossman (2011) being reflective involves making explicit, contributing factors around the researcher that others may associate with bias. For example, the researcher may need to ask of themselves the following (not exclusively): What the role of the researcher is, what the research assumptions are, whether the researcher has a personal or funding connection to the research or to the participants, and if there is a personal story that may influence how the researcher conducts the study and or interprets the results.

Reflexivity equates to a type of self-awareness that involves an honest description of the researcher’s role, beliefs, training, expectations and assumptions (Hansen, 2006). Being reflexive therefore, ensures that the researcher approaches their role in the research with an awareness of how their personal story and context can influence the gathering and analysis and interpretation of information elicited.

Reflexivity in Practice

My reasons for writing a thesis in this area stem from both personal and professional experience. It is these experiences that may have influenced my attitudes and assumptions toward this topic. Throughout the process of
undertaking this research I have constantly reflected on the reasons behind my choices. These choices included whom I sought as supervisor, the topic I wanted to research, individuals I wished to interview, my approach to the interviews, the questions I asked, data analysis, and the writing up of results and reports. That which follows is an account of the experiences I have revisited and reflected upon during my doctoral candidature.

My interest in this area began 34 years ago when I first started my career as a psychologist in a community-based, multi-disciplinary mental health clinic. This first experience shaped how I viewed mental illness and how I would work with both the staff that provided the service and the individuals and their families who received it.

Our clientele who suffered from the most severe psychiatric illnesses rarely required hospitalisation. In addition to individual therapy sessions offered on an out-patient basis, the clinic also ran a day program where patients could attend from 9 am to 3.30 pm, Monday to Friday. Each therapist could rely on the other staff from different disciplines to contribute their individual expertise in the treatment of the patients we offered a service to. Every morning the day programme patients would meet together with staff and discuss the day’s activities. Time for reflection was offered with patients encouraged to discuss aspects of the service they found beneficial and identify aspects requiring change. As a consequence, the programmes offered were constantly being discussed and modified to meet the needs of the patients. Everyone had a voice and every voice was heard.

The multi-disciplinary team approach to service delivery that I experienced working in the adult sector, ensured that caring for and carrying risk
associated with providing mental health services, was shared amongst all team members. If I had a patient whom I was seeing on an outpatient basis and who could benefit from more intensive treatment or required closer monitoring, a discussion with all team members would likely result in direct acceptance of that patient into the day program. There was a mutual expectation that if a request for this type of intervention was requested, then it was likely warranted and acceptance of the referral would often pass unchallenged. This process was the same for hospital admission. By the early 90’s however, the adult mental health system underwent major change and referral from one treatment environment to another, no longer became a simple and unchallenged process. Teams became ‘specialised’ and referral from one team to another became a process of multiple assessments with no guarantee of acceptance of the referral. A noticeable change in staff regarding perceived ability to provide a thorough and safe environment of care also occurred.

My move from community-based services in the adult sector, to child and adolescent inpatient services, only strengthened my belief that accessibility, appropriateness and availability of services and supports offered in a safe environment by well qualified staff working in collaboration with other clinicians, service providers, and consumers, was paramount in order to provide an appropriate model of care that benefitted all. However, such an approach to service delivery was not always possible, particularly when attempting to coordinate child and adolescent mental health services across treatment sites.

The experience of working in both adult community based mental health services as well as child and adolescent inpatient services, heavily influenced my decision around my doctoral research topic. Mindful of this and of my position as
the clinical psychologist on the inpatient unit from which I would be recruiting potential study participants, I ensured that the audit trail began at the moment I had formulated the study. I was clear from the onset that the purposes of the research were to identify from the participant perspective: their experiences with mental health services, how the services could improve, where gaps were, where processes or outcomes were unsatisfactory, and to look at coming up with possible solutions for change or improvement. I tried to instill in the participants an understanding that the study was an opportunity for them to be heard and to potentially make a difference in future service design and delivery.

The qualitative study meant that I would have the privilege of interviewing all three consumer groups accessing the inpatient unit. In every interview I made sure the opening question was not leading. I made conscious efforts throughout each of the interviews to make the participant feel relaxed and safe about speaking and sharing their experiences, no matter how negative they might be. The audit trail I kept and referred to before and after each interview, ensured that I found a correct balance and approach. Referring clinicians appeared very comfortable about providing any negative experiences or comments and were equally forthcoming about positive experiences. Parents and carers and the young people themselves, all appeared relaxed and confident in telling their stories exactly as they experienced them, not holding back and being prepared to explain further when requested. Ensuring that each participant felt comfortable and felt able to speak freely without repercussion on all issues of relevance and importance to them was and remained throughout the entire process, of paramount importance.
CHAPTER 2
SATISFACTION WITH CHILD AND ADOLESCENT PSYCHIATRIC INPATIENT CARE: THE CONSUMER PERSPECTIVE: A SYSTEMATIC REVIEW

Status of paper: ‘Text in Manuscript’

Authors:
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Statement of Authorship

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**Principal Author**

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<tr>
<th>Name of Principal Author (Candidate)</th>
<th>Gigetta Maria Luigia Salamone-Violi</th>
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<tbody>
<tr>
<td>Contribution to the Paper</td>
<td>I was responsible for the conception of the research upon which this paper is based. I conducted the search and retrieved all relevant titles and abstracts. I conducted the data extraction and analysis. I produced the first draft of the manuscript and will submit the final manuscript. I will act as corresponding author.</td>
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<tr>
<td>Certification:</td>
<td>This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.</td>
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**Co-Author Contributions**

By signing the Statement of Authorship, each author certifies that:

i. the candidate’s stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the
thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate’s stated contribution.

<table>
<thead>
<tr>
<th>Name of Co-Author</th>
<th>Professor Anna Chur-Hansen</th>
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<tbody>
<tr>
<td>Contribution to the Paper</td>
<td>Assisted in the initial stages of conceptualization of the research, checked the list of predefined criteria making up the critical appraisal tool for assessing quality of papers reviewed, participated in the assessment of two papers in this systematic review (one quantitative, one qualitative), to ensure consistency of ratings against the predefined criteria, read the completed draft and made suggestions providing editorial input.</td>
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<tr>
<th>Name of Co-Author</th>
<th>Professor Helen Winefield</th>
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<tr>
<td>Contribution to the Paper</td>
<td>Helped to evaluate and edit the manuscript.</td>
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Abstract

Research on satisfaction with child and adolescent psychiatric inpatient care is limited. The purpose of this systematic review of the literature was to examine aspects of a child and adolescent inpatient admission which consumers found satisfactory.

PubMED, PsychINFO, Embase and Scopus were searched for both quantitative and qualitative studies. A quality assessment and synthesis of the data (based on Joanna Briggs Institute guidelines) was completed on studies that examined consumer satisfaction with child and adolescent mental health services that included inpatient care.

Fourteen studies met the inclusion criteria, seven qualitative and seven quantitative. The review demonstrated the lack of uniformity in use of instruments and approaches in measuring satisfaction, resulting in variability across the studies on study characteristics and outcome measures making pooling of results difficult, and comparisons across sites not possible. The narrative synthesis clarified the concept of satisfaction with psychiatric inpatient care. For all three consumer groups, positive interactions with other staff and patients, perceived changes in the reasons for admission or referral, interventions that included carers and referring clinicians, and good discharge and follow-up plans, were identified as satisfactory aspects of the mental health services, with the absence of same resulting in an unsatisfactory experience.

The small number of studies in this literature review yielded variability across all measures and suggests further research that requires carefully conceived and executed investigations taking into consideration the need for methodological stringency.

Keywords: satisfaction, child and adolescent, inpatient care, mental health, psychiatric
Introduction

Consumer satisfaction is an important indicator of health care outcome (Brunero, Lamont, & Fairbrother, 2009; Heidegger, Saal, & Nuebling, 2006; Lambert, Salzer, & Bickman, 1998) and is useful in the inpatient setting to identify which aspects of treatment/intervention are useful and relevant and which are not (Gavidia-Payne, Littlefield, Hallgren, Jenkins, & Coventry, 2003). As satisfaction with a service has been found to be related to an individual’s subsequent use and compliance with treatment (Fitzpatrick, as cited in Fitzpatrick & Hopkins, 1993; Jin, Sklar, Min Sen Oh, & Chuen, 2008) addressing predictors of dissatisfaction may prevent unplanned cessation of therapy (Barber, Tischler, & Healy, 2006).

Determining satisfaction regarding a particular service can only be done comprehensively by gathering information from all of the relevant stakeholders. Early research in child and adolescent mental health satisfaction focussed primarily on the satisfaction ratings of the parent/carer (Bradley & Clark, 1993; Hefflinger, Simpkins, Scholle, & Kelleher, 2004). The focus on parental ratings was based on the belief that young people may not have been at a developmental stage capable of contributing meaningful information.

Whilst the views of parents/carers of children and young people with mental illness continues to be extremely important in service planning and delivery (Tas et al., 2010), with the drive towards consumer participation at all levels the input of young people is now sought. This inclusion has occurred, not only because a young person’s input is valued, but also because evidence suggests that young people and their parents/carers’ satisfaction levels with mental health services and service delivery are only minimally to moderately
correlated (Brunero, 2009; Garland, Aarons, Hawley, & Hough, 2003; Kaplan, Busner, Chibnall, & Kang, 2001).

As important as carers are in the treatment of their child, so too is the role of the referring clinician. However, understanding the needs and supports required by referring mental health clinicians in the provision of ongoing care for young people, is an area with extremely little published research. This is an omission with potentially flawed outcomes in regards to future service design, with studies indicating that the perspective of the referrer regarding effective service delivery often differs from that of other stakeholders, such as administrators, the patient, as well as the patient’s other family members (Brunero et al., 2009). This specific perspective therefore, also warrants consideration.

The aim of this systematic review was to explore the existing international literature, in order to identify studies relevant to child and adolescent psychiatric inpatient care from the perspective and experiences of referring clinicians, and children and adolescents, as well as their carers. This review aims to improve and expand on other reviews by including all aspects of the inpatient experience, including post discharge experiences of young people and their carers. Reporting of this systematic review follows PRISMA (Moher, Liberati, Tetzlaff, & Altman, 2009) and Joanna Briggs Institute (JBI) guidelines (2011).

**Methodology**

**Data Sources and Search Strategy**

Qualitative or quantitative studies published in English were included in the review. Inclusion criteria were; a psychiatric inpatient admission of a child or adolescent restricted to children and adolescents up to the age of 18 years,
sufficient information on the level of satisfaction around admission experienced by children, adolescents, carers of children and adolescents, and where included, referring clinicians, expressed as interview responses, focus group results, narratives for qualitative studies, and survey and questionnaire data for quantitative studies (see Figure 1 below).

The search strategy aimed to locate both published and unpublished studies. A three-step search was utilised. In order to identify potential key words a limited search of PubMed and PsychINFO was identified. This was followed by analysis of the text words contained in both the title and abstract, in addition to index terms used to describe the article. The second search involved all identified key words and index terms undertaken across all included databases. Third, the reference lists of all identified reports and articles were searched for additional studies. The search was performed on PubMed, PsychINFO, Embase and Scopus, with no limitations. Each database was searched from its onset until July 2016 with no publication date restrictions. Multiple keywords and medical subject headings (MESH Terms) for psychiatric care, satisfaction and inpatient were combined (see Table 1 below).
Figure 1. Flowchart of study selection

1. Potentially relevant papers identified by literature search
   (N= 1194)

2. Papers retrieved for detailed examination
   (n = 52)

3. Papers excluded after evaluation of abstract as clearly not relevant
   (n = 1142)

4. Papers excluded after review of full paper
   (n = 38)

5. Reasons for exclusion:
   - Review paper
   - Non-English paper
   - Adult population
   - Outpatient only
   - Non-Psychiatric
   - Treatment specific

6. Trials included in systematic review
   (n=14)

7. Outcomes measured
   Satisfaction:
Table 1. Search strategy terms by database

<table>
<thead>
<tr>
<th>PubMed</th>
<th>PsychINFO</th>
<th>Embase</th>
<th>Scopus</th>
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</table>
Study Selection, Critical Appraisal, and Risk of Bias Assessment

All relevant titles and abstracts (N=1194) were retrieved. Full text publications of studies that were potentially eligible for inclusion (N=38) were read and checked against the criteria. Fourteen papers that met the eligibility criteria were included in the final review.

The included studies were assessed according to the list of predefined criteria (MAStARI critical appraisal tool) as outlined in the JBI guidelines (2011). The list of criteria appears in the first column of Tables 2 and 3 below. The appraisal tool was developed and refined by the first and second authors who then independently evaluated the same two papers, one quantitative and one qualitative. The first author evaluated all subsequent papers included in the review. Quantitative and qualitative studies were separately evaluated with the appropriate criteria sets, and a quality score expressed in percentage produced for each individual study according to the degree to which they met the relevant criteria set. ‘High quality’ was indicated by a score of 70% or more; ‘average quality’ was indicated by a score of 50-69%; and ‘low quality’ was indicated by a score of less than 50%.

Data extraction and analysis.

Data were extracted from included papers on methodology, setting, study population, age of participants, aims, length/duration of treatment, and measurement and outcomes of satisfaction. Studies were grouped based on their design (quantitative and qualitative). Quality of evidence, outcomes measured, reported results, as well as study strengths and limitations, are all discussed. A summary of the reported results from each study can be located in Table 4.
Results: Quantitative

The results of the search are shown in Figure 1. Of the fourteen studies included in the final review (Table 4), seven were quantitative (Blader, 2007; Gowers, Crisp, Joughin, & Bhat, 1991; Heflinger et al., 1996; Kaplan et al., 2001; Marriage, Petrie, & Worling, 2001; Rey et al., 1999; Tas et al., 2010) and seven qualitative (Biering & Jensen, 2011; Geraghty, McCann, King, & Eichmann, 2011; Gill et al., 2016; Haynes, Eivors, & Crossley, 2011; Oruche, Gerkensmeyer, Stephan, Wheeler, & Hanna, 2012; Richardson, Cobham, McDermott, & Murray, 2013; Salamone-Violi, Chur-Hansen, & Winefield, 2015). Data on the quality assessment (based on JBI guidelines) of the included studies are provided in Table 2 (quantitative studies) and Table 3 (qualitative studies).
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<tbody>
<tr>
<td>1. Has the purpose of the survey been stated?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>2. Is there a statement around the information to be gathered?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>3. Has the target population been clearly defined?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>4. Was the treatment setting identified and described?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>5. Has sampling procedure been explained?</td>
<td>Partially</td>
<td>X</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>6. Is the group surveyed a true representation of the population?</td>
<td>X</td>
<td>✓</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>7. Has selection error been addressed? (Does everyone have an equal chance of being selected)</td>
<td>Not clear</td>
<td>Not clear</td>
<td>X</td>
<td>Not stated</td>
<td>✓</td>
<td>Not stated</td>
<td>Inferred</td>
</tr>
<tr>
<td>8. Has anonymity and or confidentiality been explained?</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
</tr>
<tr>
<td>9. Has a rationale behind the question wording been provided?(open, closed, open-response questions etc)</td>
<td>X</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>N/A</td>
<td>✓</td>
</tr>
<tr>
<td>10. Are the survey questions reflective of the aims of the study?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>11. If a measurement scale was used was it appropriate for respondents?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Question</td>
<td>Yes</td>
<td>No</td>
<td>Partial</td>
<td>Insufficient</td>
<td>N/A</td>
<td>Rating</td>
<td></td>
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</tr>
<tr>
<td>12. Has the method of data collection been explained?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>13. Has the survey instrument been tested for validity and reliability?</td>
<td>X</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>Partial</td>
<td>N/A</td>
<td>X</td>
</tr>
<tr>
<td>14. Were any standardised instruments used?</td>
<td>X</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
</tr>
<tr>
<td>15. Was the survey instrument piloted before use in the study?</td>
<td>Not stated</td>
<td>Not stated</td>
<td>N/A</td>
<td>Not stated</td>
<td>X</td>
<td>N/A</td>
<td>No</td>
</tr>
<tr>
<td>16. Was appropriate statistical analysis used?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>17. Was non-response error addressed?</td>
<td>Not stated</td>
<td>Not stated</td>
<td>Not stated</td>
<td>Not stated</td>
<td>✓</td>
<td>Not stated</td>
<td></td>
</tr>
<tr>
<td>18. Do the conclusions drawn from the research report flow from the analysis or interpretation of the data?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>19. Are strengths of the study stated?</td>
<td>X</td>
<td>X</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>20. Are limitations of the study stated?</td>
<td>X</td>
<td>✓</td>
<td>✓</td>
<td>Partially</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
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<td>21. Is there a statement around ethics?</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Rating</td>
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<td>66.66%</td>
<td>71.43%</td>
<td>52.38%</td>
<td>71.43%</td>
<td>71.43%</td>
<td>66.66%</td>
</tr>
</tbody>
</table>
Study Characteristics: Quantitative Studies

The mean quality score for the quantitative studies was 63.60% (moderate quality), with a range of 45.24% to 71.43%. Three studies (Blader, 2007; Marriage et al., 2001; Rey et al., 1999) had a high quality score (>70%), three studies (Heflinger et al., 1996, Kaplan et al., 2001, Tas et al., 2010) had a moderate quality score (50-69%), and one study (Gowers et al., 1991) had a low quality score (<50%).

Data collection.

The specific outcomes measured across studies were varied both in type and in the way they were measured. In all of the seven studies, outcomes assessed subjective experiences around satisfaction with the services received. Self-designed and/or modified questionnaires were used to measure outcome in 5 of the 7 studies (Gowers et al., 1991; Heflinger et al., 1996; Kaplan et al., 2001; Rey et al., 1999; Tas et al., 2010). Two studies reported testing for internal consistency of their modified rating scale which was found to be adequate to demonstrate reliability (Heflinger et al., 1996) or high (Rey et al., 1999). The remaining two studies (Blader, 2007; Marriage et al., 2001) utilised standardised rating scales such as the Child Global Assessment Scale (CGAS) (Shaffer et al., 1983), the Child Behavior Check List (CBCL) (Achenbach & Edelbrock, 1991), the Youth Self Report (YSR) (Achenbach, 1991) and the Client Satisfaction Questionnaire (CSQ) (Attkisson & Zwick, 1982). Clinical ratings around treatment outcome were included in two studies (Marriage et al., 2001; Rey et al., 1999). In one study (Rey et al., 1999), two clinicians rated outcome. Interrater reliability was tested and shown to have moderate agreement in outcome rating (k = 0.58).
Four of the seven studies (Blader, 2007; Kaplan et al., 2001; Marriage et al., 2011; Rey et al., 1999) reported varying levels of drop-out, resulting in diminished ability of the population surveyed being a true representation. In one study (Rey et al., 1999), only 60% of parental questionnaires were returned. In another study (Marriage et al., 2011), 18% of families declined to participate in the follow-up part of the study and of those who had agreed to participate, 16% dropped out over the four months after discharge. In the study by Kaplan et al. (2001), of the 95% of patients agreed to be interviewed; only 67% of parent/caretakers were available for inclusion of which 97% agreed to participate. In the study by Blader (2007), there was an overall consent rate to participate of only 65%, with 10% declining to participate, 10% discharged after very short stays of less than 2 days, and 15% of the children not providing consent promptly enough to obtain follow-up data.

**Treatment offered.**

The mental health services under review also varied within and between studies. Four of the seven studies were based in multi-disciplinary adolescent inpatient units that provided various combinations of inpatient, outpatient, five-day/week inpatient stay, or consultation liaison services (Gowers et al., 1991; Heflinger et al., 1996; Rey et al., 1999; Tas et al., 2010). Three of the seven studies under review obtained their population sample in their entirety from inpatient admissions (Blader, 2007; Kaplan et al., 2001; Marriage et al., 2001). Two of the studies (Marriage et al., 2001; Tas et al., 2010) offered specific information around the types of service the inpatient unit provided, including a structured program with ward activities and attendance at the hospital school, as well as group therapies. Short-term treatment included individual, group and
family therapy (Marriage et al., 2001). Other services included a multi-model treatment service based on psychodynamic, cognitive-behavioural, educational, and family psychotherapies, as well as pharmacotherapy (Tas et al., 2010).

Satisfaction ratings were compared across the different services offered in only one of those studies (Rey et al., 1999). One further study (Helfinger et al., 1996) included a comparison group from a different site offering a different form of service delivery (traditional mental health services compared to traditional mental health services plus additional case management components of care). Satisfaction measures were compared between the two sites. The remaining two studies pooled results for the different service delivery methods, making differentiation regarding satisfaction relevant to service type, not possible.

Length of stay was reported in 5 of the 7 studies (Helfinger et al., 1996; Kaplan et al., 2001; Marriage et al., 2001; Rey et al., 1999; Tas et al., 2010). One study (Helfinger et al., 1996) reported length of stay as ‘one month minimum in treatment’ in order to be included in the study. No average length of stay for all participants was reported. Another study also described length of stay as a five day a week inpatient stay (week-ends home) without providing a mean length of stay for all subjects (Rey et al., 1999). The average length of stay for participants in the remaining 4 studies, ranged from 12-13 days (Geraghty et al., 2011), to 75.7 days (Tas et al., 2010).

**Population characteristics.**

Outcome measures were also specific to the population under study. One study population was restricted to clinicians who had referred or were able to refer to an adolescent inpatient unit (Gowers et al., 1991), two included parents and children (Helfinger et al., 1996; Tas et al., 2010), two parents only (Blader,
2007; Kaplan et al., 2001), one parents and clinicians (Rey et al., 1999) and one, all three consumer groups: referrers, parents and children (Marriage et al., 2001).

One of the studies (Gowers et al., 1991) focusing on referrer perceptions of mental health services, did not include either the age range of young people clinicians had referred to or would consider referring to the service, nor the age population for which the adolescent unit in question was designed for. For the remaining six studies reviewed, the age range of consumers varied from 3-18 years. Mean age was provided in only 5 other studies (Blader, 2007; Kaplan et al., 2001, Marriage et al., 2001; Rey et al., 1999; Tas et al., 2010) and ranged from 9.5 years (Blader, 2007), to 15.3 years (Tas et al., 2010).

**Referrer satisfaction.**

Only one study included the perceptions of clinicians alone around referral to an adolescent inpatient unit (Gowers et al., 1991). Child psychiatrists were found to be the profession most likely to refer to the adolescent unit, with the most frequent reason for referral, ‘specialisation in the adolescent age range’, and the most frequent diagnosis of adolescents referred, ‘psychosis’ and ‘eating disorders’. There was no significant difference between the professions on the basis of overall satisfaction with services offered which were found to be ‘completely’ or ‘on the whole,’ satisfactory. Communication, liaison and prompt response to crisis were identified as valued components of the service offered, in addition to the inpatient unit’s ability to manage severe psychiatric illness.

It is of importance to note that in this sole study, 83% of the total questionnaires were returned and of the professions surveyed, return rates varied considerably: 73% for CPNs (Nurse Practitioners), 94% from paediatricians, and 93% return rate from child and adolescent psychiatrists, the latter group having
made the most referrals to the unit in the past and the group most likely to refer again in the future. No explanation was offered by the authors to explain the return rate. It is possible that professions or individuals within professions in favour of an adolescent mental health unit had greater incentive to reply.

**Clinician ratings.**

Three other studies included the ratings of clinicians around outcome, comparing this to parental satisfaction around care received by their child (Marriage et al., 2001; Rey et al., 1999; Tas et al., 2010). In one study (Rey et al., 1999), outcome was dichotomised as ‘positive’ (goals of treatment achieved) versus ‘doubtful’ or ‘negative’.

In the other study (Marriage et al., 2001), clinicians used the CGAS scale to rate the level of functioning. In the third study (Tas et al., 2010), clinicians used a Likert type scale in order to evaluate the progress of the young person on individual psychopathology and family functioning. All three studies reported some improvement in clinical outcome as a consequence of the inpatient experience. However, in one study (Rey et al., 1999), inpatients and females were found to be 1.7 times as likely to have been given a negative outcome, compared to outpatients and males respectively. In another study, the majority of clinicians rated the overall improvement as ‘partly better’ as opposed to ‘much better’ or ‘no change’ (Tas et al., 2010). Another study (Marriage et al., 2001) reported a significant correlation between overall ratings of satisfaction and perceived improvement in the presenting problem among referring clinicians. Clear and practical recommendations for post discharge management were more important for referring clinicians in this study, than was improvement in the child’s clinical state whilst an inpatient.
Parental satisfaction.

All of the studies reporting parental perceptions of care for the inpatient admission of their child reported overall satisfaction with the service provided. However, two studies reported satisfaction levels deteriorating over time post discharge (Blader, 2007; Marriage et al., 2001), whilst another reported no change in parental satisfaction post discharge (Rey et al., 1999). The reasons for decline in satisfaction were related to deterioration around gains made as a consequence of the inpatient experience. The rated decline in satisfaction was reported most by parents of children with externalising behaviour.

Two studies have reported parental satisfaction with services comparing outpatient and inpatient experiences. One study (Rey et al., 1999) reported greater satisfaction with inpatient services, the other (Heflinger et al., 1996) the opposite. Improved satisfaction correlated with perceptions that inpatient services met the child’s and family’s needs better than outpatient services.

Overall parent satisfaction was associated with; willingness to return to the service again (Rey et al., 1999), relative ease in accessibility to service offered (Heflinger et al., 1996), financial cost involved in accessing and utilizing the services (Heflinger et al., 1996), living conditions within the unit (Marriage et al., 2001), and relationship with staff (Marriage et al., 2001; Tas et al., 2010). One study showed the usefulness of the discharge recommendation as having influenced overall parental satisfaction (Marriage et al., 2001). Parental satisfaction was not related to clinical outcome in one study (Heflinger et al., 1996) but was found to be so in two others (Blader, 2007; Rey et al., 1999).

One study included comments from parents around improvement in service delivery and its relationship to overall satisfaction (Marriage et al., 2001).
This once again focussed on providing a positive and informative relationship with staff, and inclusion in treatment plans during and post discharge. Source of dissatisfaction occurred when there was perceived friction with staff, and when the ward was viewed as a place of restriction and confinement and lacking in flexibility (Marriage et al., 2001). No correlation was noted between length of stay (LOS) and parental satisfaction with services in two studies (Blader, 2007; Marriage et al., 2001).

Child/adolescent satisfaction.

One study reported overall adolescent satisfaction as being related to the admission process itself (Tas et al., 2010). Two studies identified an association between child and adolescent satisfaction and perception of the living conditions within the inpatient unit (Kaplan et al., 2001; Marriage et al., 2001). Two studies identified a correlation between satisfaction and the relationship experienced with staff (Marriage et al., 2001; Tas et al., 2010). One study identified helpfulness of discharge recommendations as related to adolescent satisfaction (Marriage et al., 2001), whilst another reported satisfaction to be influenced by the nature of the individual and family sessions provided (Tas et al., 2010). Two studies reported a relationship between satisfaction and participation in outings (Kaplan et al., 2001; Tas et al., 2010), whilst another linked satisfaction with perception that the problem at admission had improved (Kaplan et al., 2001). No link between satisfaction and symptomatic or functional improvement was found in another study (Marriage et al., 2001). This suggests satisfaction to be related to individual needs and expectations of the consumer.

One study was found to link dissatisfaction to negative interpersonal experiences with staff and/or other patients, along with perceived lack of
privacy, harsh discipline for behaviour and ward rules (Marriage et al., 2001). Lack of information around the illness and treatment as well as a poor perception around ward facilities were also associated with dissatisfaction in another study (Tas et al., 2010). Another investigation specifically asked questions around abuse experienced or perceived (Kaplan et al., 2001). Perceptions or experiences with abuse were linked to dissatisfaction. No correlation was found between parental and child satisfaction in one study, highlighting the importance of individual responses in determining satisfaction around services offered (Marriage et al., 2001).

**Summary Quantitative**

Of the seven quantitative studies included in this systematic review, all claimed significant positive benefit to some degree around the inpatient experience for children and adolescents. However the outcomes measured, the sample sizes and the data presented varied extensively. Direct comparison of the studies therefore is limited, and reliable conclusions cannot be drawn.

There are a number of limitations applicable to individual studies, as well as to all of the studies on the whole. Only one study applied a quasi-experimental design comparing satisfaction across two different types of service delivery (Heflinger et al., 1996). This study however, targeted only children of service personnel in the United States, with services specifically and exclusively designed for this population. Two of the studies were longitudinal and included satisfaction ratings at discharge and post discharge time intervals (Blader, 2007; Marriage et al., 2001). The remaining studies all rated satisfaction at one time level, at time of discharge or within weeks thereafter. Therefore, whether satisfaction with services continued over time could not be established.
In addition, all seven of the inpatient quantitative studies identified varied in type of inpatient setting, age range of service consumers, number of participants, diagnostic categories, as well as length of stay. Generalization of results was therefore not possible. The variances noted here might all have impacted on perceptions of care. For example, expectations around care are arguably different for parents/carers of six year olds, compared to young people about to enter the adult system (at age 18). Length of stay may also have contributed to a difference in intervention offered, with longer-term patients likely to receive and perceive interventions/treatment offered in a different way to those with an acute or crisis admission of 24 hours or less. Although two studies (Blader, 2007; Marriage et al., 2001) claimed no relationship between length of stay and satisfaction, the focus was on parental perceptions and not on the perceptions of the young people actually receiving care.

Other limitations inherent in the studies reviewed included; diagnoses made clinically, rather than on structured interviews (Marriage et al., 2001), multiple clinicians being used to rate patients, thus making it impossible to establish interrater reliability (Marriage et al., 2001; Rey et al., 1999), and several studies using questionnaires that were modified specifically for the setting in which the studies were being conducted, without having their psychometric properties explored (Gowers et al., 1991; Kaplan et al., 2001; Marriage et al., 2001; Rey et al., 1999; Tas et al., 2010). Whereas there is an argument for designing satisfaction questionnaires that specifically address the service being appraised, only one study (Tas et al., 2010) made an attempt to test for the appropriateness of design. It failed however to pilot the questionnaire before inclusion.
A further limitation of the studies involved the pooling of results around satisfaction, derived through the use of multiple services (inpatient, outpatient, residential), without differentiation (Gowers et al., 1991, Rey et al., 1999). This may not have accounted for potentially different expectations around care. Outpatient and inpatient services are not the same, and expectations around care specific to particular services may also affect satisfaction levels. It is therefore important to differentiate satisfaction perceived for different services received. One study (Rey et al., 1999) suggested that easy access to services and convenience of appointments for example, are of greater importance to individuals receiving outpatient care than for those who are receiving inpatient treatment. Another study (Heflinger et al., 1996) suggested that in inpatient services, it might be more difficult to affect change in practice due to the more severe nature of illness that is often treated in an inpatient unit. Expectations around care and service delivery, according to study authors, are therefore likely to vary.

Results: Qualitative

Study Characteristics

The mean quality score for the qualitative studies was 74.88% (high quality), ranging from 58.82% to 100%. Six studies had a high quality score (Biering & Jensen, 2011; Gill et al., 2016; Haynes et al., 2105; Oruche et al., 2012; Richardson et al., 2013; Salamone-Violi et al., 2015), whilst the remaining study (Geraghty et al., 2011) had a moderate quality score (see Table 3 below).
Table 3. Results of Quality Assessment for Qualitative Studies (Based on JBIQARI Checklist Criteria)

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Is there congruity between the stated philosophical perspective and the research methodology?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>2. Are the research questions appropriate for the methodology applied?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>3. Has the recruitment of participants been appropriately explained?</td>
<td>✓</td>
<td>✓</td>
<td>N/A</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>4. Are the participants a true representation of the population under study?</td>
<td>✓</td>
<td>Unclear</td>
<td>✓</td>
<td>No</td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Is exclusion criteria of participants described?</td>
<td>✓</td>
<td>Not stated</td>
<td>Not stated</td>
<td>Not stated</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>6. Is inclusion criteria of participants described?</td>
<td>No</td>
<td>✓</td>
<td>Unclear</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>7. Is the method of data generation explained?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>8. Is there a statement around saturation?</td>
<td>✓</td>
<td>Focus Group</td>
<td>Content Analysis of records</td>
<td>N/A</td>
<td>No</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>9. Is the method of data extraction explained?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Question</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>N0</td>
<td>No</td>
<td>No</td>
<td>✓</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-----</td>
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<td>----</td>
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<td>----</td>
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<td>----</td>
</tr>
<tr>
<td>10. Is the interpretation of results congruent with the methodology applied?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>11. Is there a statement locating the researcher culturally?</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>N0</td>
<td>No</td>
<td>No</td>
<td>✓</td>
</tr>
<tr>
<td>12. Is there a statement locating the researcher theoretically?</td>
<td>✓</td>
<td>No</td>
<td>No</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>13. Is the influence of the researcher on the research and vice-versa addressed?</td>
<td>N/A</td>
<td>No</td>
<td>✓</td>
<td>No</td>
<td>✓</td>
<td>Partially</td>
<td>✓</td>
</tr>
<tr>
<td>14. Are participant responses reflecting the identified themes?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>15. Has anonymity been explained?</td>
<td>✓</td>
<td>✓</td>
<td>N/A</td>
<td>✓</td>
<td>No</td>
<td>No</td>
<td>✓</td>
</tr>
<tr>
<td>16. Has ethics approval been stated?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>17. Do the conclusions drawn from the research report flow from the analysis or interpretation of the data?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>18. Are strengths of the study stated?</td>
<td>Unclear</td>
<td>✓</td>
<td>✓</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>✓</td>
</tr>
<tr>
<td>19. Are limitations of the study reported?</td>
<td>✓</td>
<td>✓</td>
<td>No</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>%</td>
<td>72.2%</td>
<td>72.22%</td>
<td>58.82%</td>
<td>73.68%</td>
<td>73.68%</td>
<td>73.68%</td>
<td>100%</td>
</tr>
</tbody>
</table>
Similar to the quantitative studies discussed earlier, the qualitative studies in the review also varied considerably in regards to participant recruitment, mental health setting, duration of treatment, and methodology used for data collection and analysis, making direct comparison between the studies difficult.

Although all studies included participants or carers of young people who had experienced an inpatient admission, four studies (Gill et al., 2016; Haynes et al., 2011; Oruche et al., 2011; Richardson et al., 2013) included participants from more than one site without differentiating between them in the reporting of findings. The average length of stay for inpatient care across the seven studies could also not be determined, as one study did not report length of stay (Oruche et al., 2012), one other study did not differentiate between inpatient or outpatient care when determining length of time in treatment (Richardson et al., 2013), whilst another provided an average length of stay across the three different inpatient units in their study (Gill et al., 2016). Of the six studies that did report length of stay for inpatient care only (n=3), the range varied from 4 days (Salamone-Violi et al., 2015) to 36 months (Haynes et al., 2011).

Four of the seven studies reported perceptions around satisfaction in adolescent populations only (Biering & Jensen., 2011; Gill et al., 2016; Haynes et al., 2011; Salamone-Violi et al., 2015), whilst the remaining three reported perceptions of satisfaction among carers of young people receiving mental health services. Only one of the seven studies under review did not employ face-to-face interviews with participants (Geraghty et al., 2011). This study took the form of a content analysis of records of consultation between consumer consultants and families/carers of children admitted into an acute inpatient unit. Consensual Qualitative Research (CQR) was the method used to analyse the data collected.
over a two-year period. Although the process of content analysis is an appropriate method of analysis originally designed to analyse the records of psychotherapy sessions (Geraghty et al., 2011), an assumption is made that the content recorded is an accurate and complete record of the interaction and not a summary of what the author recalls, or considered relevant. This must be taken into consideration when reviewing the results. The remaining six studies employed structured or semi-structured interviews for data collection. All interviews were audiotaped before being transcribed but only one study (Salamone-Violi et al., 2015) provided participants with an opportunity to view transcripts and confirm content, or make changes before data analysis.

Methodology applied in data analysis included grounded theory method in one of the studies (Haynes et al., 2011) in order to generate codes and to advance the direction of the emerging theory around satisfaction. Thematic analysis was applied in three of the seven studies under review (Gill et al., 2016; Richardson et al., 2013; Salamone-Violi et al., 2015), whilst one of the seven studies (Biering & Jensen, 2011) applied a hermeneutic methodology in collecting and analysing data aimed at understanding how adolescents perceive the quality of psychiatric inpatient care. An interview guide was developed in order to address the research questions in this study. Initial stages of data interpretation were conducted following the guidelines of Appleton and King (1999), followed by thematic analysis (Van Manen, 1990) in order to transfer understanding into concepts. One other study (Oruche et al., 2012) applied content analysis to data gained from semi-structured focus group interviews. This study employed five focus groups to gather data. However, the focus groups were not equally distributed, with one “group” comprising of only one participant. This was most likely a one-
to-one interview that may have yielded results different to those where other individuals in groups also have access to the opinions of others. The authors did not address this discrepancy.

**Parental/carer satisfaction findings.**

Of the three studies that reviewed satisfaction from the perspective of parents-carers, mainly negative experiences were reported. Concerns around their child’s mental health treatment included perceptions that the inpatient unit was unsafe, un-therapeutic, and staffed by critical or unresponsive staff. However, in those individuals who did report positive experiences, the opposite was expressed. In all three studies (Geraghty et al., 2011, Oruche et al., 2012, Richardson et al., 2013), parental satisfaction was influenced by positive interactions with staff, experiencing support from staff, as well as receiving support from others both from within mental health services as well as from other family and friends.

Parental experiences around having a child with mental illness also focussed mainly on the difficulties encountered by parents. One study (Geraghty et al., 2011) reported high levels of parental distress, anxiety, guilt, and feelings of isolation. Grief, a profound sense of loss, exhaustion, and worries and concern around the future prospects for their child, were also identified in two of the studies (Oruche et al., 2012, Richardson et al., 2013). One study (Oruche et al., 2012) highlighted parental concerns around disruption to family routine, barriers and difficulties in accessing services, and waning support as all contributing to the difficulties experienced in having a child with mental illness. In each of the three studies, parents/carers expressed a desire for additional support. Two studies (Geraghty et al., 2011, Richardson et al., 2013) highlighted the need for
further education around the illness prognosis and treatment, as well as more empathy from staff, and greater opportunities to talk and self-reflect (Richardson et al., 2013).

**Child/adolescent satisfaction.**

Each of the four studies (Biering & Jensen, 2011; Gill et al., 2016; Haynes et al., 2011; Salamone-Violi et al., 2015) that looked at child/adolescent satisfaction identified themes around the young person’s experience that were either negative or positive. Common themes across the four studies included; aspects around relationships with staff and other patients, interventions, the environment in which treatment was delivered, perceived clinical outcomes, as well as perceptions of discharge and what that meant for the young person. Positive experiences around each of these themes were linked to expression of satisfaction, whilst negative experiences, were linked to dissatisfaction.

**Relationship with staff and other patients.**

All four of the studies reported satisfaction among young people and the inpatient experience around a sense of connection with others experiencing similar problems. Two studies (Biering & Jensen, 2011; Gill et al., 2016) reported young people as experiencing a sense of peer solidarity, validation and belonging, whilst the other two studies (Haynes et al., 2011; Salamone-Violi et al., 2015), reported satisfaction among young people who developed positive and supportive relationships with other patients on the ward. All four studies reported that the interaction with other staff heavily influenced satisfaction with the inpatient experience. In each of the four studies, a lack of connectivity to either staff or patients resulted in an unsatisfactory inpatient experience.
**Interventions.**

Two studies (Biering & Jensen, 2011; Salamone-Violi et al., 2015) reported that young people were satisfied with interventions that resulted in their families having a better understanding of their problems (family based meetings/therapy), and that allowed free expression and opportunities to discuss their concerns. One study (Biering & Jensen, 2011) reported young people perceived that being forced into activities that others thought would be good for them, but which they did not wish to engage in, as beneficial in the long run. Young people acknowledged the need for others to take over and make some decisions for them, with one study (Salamone-Violi et al., 2015) reporting that young people viewed admission as an opportunity for staff to advocate for them and provide support around their needs. This was viewed as a satisfactory form of intervention.

**The physical environment.**

In all four studies, the physical environment was viewed in both positive and negative terms. Whilst all four studies reported the benefits of containment the inpatient unit provided (safety, security, being ‘wrapped up in cotton wool’, constant observation), three of the studies (Biering & Jensen., 2011; Haynes et al., 2011; Salamone-Violi et al., 2015) reported that the containment provided by the inpatient unit also resulted in the young person experiencing isolation from the outside world, as being restrictive, and likened to a fake world. Three studies reported dissatisfaction with the physical layout of the inpatient units, with lack of access to an outside area (Salamone-Violi et al., 2015) and lack of enjoyable activities with very little to do, resulting in constant ruminating over problems (Biering & Jensen, 2011; Haynes et al., 2011).
Clinical outcomes.

Young people in each of the four studies expressed a sense of satisfaction with the inpatient experience if they perceived a positive change in their mental state or the problem that initially resulted in them being admitted to the inpatient unit. Individuals who experienced a positive change described greater optimism (Salamone-Violi et al., 2015), personal development and a healing of the self (Biering and Jensen, 2011), being transformed (Gill et al., 2016), and being able to rationalise and think positively (Haynes et al., 2016).

Perceptions around discharge.

Young people in two of the qualitative studies under review (Gill et al., 2016; Salamone-Violi et al., 2015) reported a sense of fear or trepidation around discharge. These young people expressed concern around going back to a normal life and how peers and family would perceive them. There was also a concern around setback, of going back to ‘square one’ (Gill et al., 2016) once discharged. In both studies (Gill et al., 2016; Salamone-Violi et al., 2015), young people expressed a desire for ongoing help and support from family, friends and community teams post discharge, with some requesting a graduated discharge allowing for opportunity to maintain or consolidate any improvements made during the inpatient experience.

Limitations

Similar to the quantitative studies, the qualitative studies under review suffered limitations that may have affected the transferability of results (see Table 4, last column). Two of the studies raise questions around the choice of interviewer/interviewee. One study (Biering & Jensen, 2011) allowed participants to select their own interviewer in the hope that this would result in a
greater willingness of participants to speak openly. Although an interview guide provided ensured a degree of consistency in interview technique, it may also have restricted the type and breadth of spontaneous comments. The authors made no comment about why some interviewers were chosen over others. Interviewer preference itself may have reflected the overall inpatient experience for the young person. One study (Gill et al., 2016) had unit staff select patients to be interviewed based on their perceived willingness to talk. These participants generally found the inpatient experience beneficial. It is possible however, that those not selected or unwilling to participate, may have done so due to dissatisfaction with the inpatient experience.

Recruitment of participants in the qualitative studies under review varied considerably. Two studies included participants that were self-referred (Oruche et al., 2012; Richardson et al., 2013), one of which (Oruche et al., 2012) had a payment incentive of $40, the other recruiting through ‘word of mouth’ and ‘flyers’. Furthermore, three of the seven studies (Gill et al., 2016; Oruche et al., 2012; Richardson et al., 2013) included participants who were ‘all mainly female’ or mothers. Inferences about those who did not participate therefore cannot be made.

Three studies (Gill et al., 2016; Haynes et al., 2011; Richardson et al., 2013) interviewed participants across different units without clarification of differences in experiences and treatments offered, whilst two studies (Oruche et al., 2012; Richardson et al., 2013) recruited carers of young people with mental illness that varied considerably in age, mental illness diagnosis, type and duration of care. It cannot be stated therefore what influence each of these factors, or one factor or combinations thereof, had on the overall perception of care.
Discussion

The systematic review undertaken in this thesis on child and adolescent psychiatric inpatient care identified very little published research in this area, and in the research that does exist, methodological inconsistencies were found across each of studies reviewed. Both quantitative and qualitative studies were of moderate to high quality, with one exception. However, with research occurring with different population groups, services offered, philosophies around care and treatment offered, as well as variable length of stay, comparisons across units were difficult to undertake and transferability of results unlikely. However, it is important to note that in each of the studies, understanding consumer desires, including suggestions around change and or modification around existing systems of care, was a stated or implied aim. It is inevitable therefore, that the findings will have greatest relevance to the site at which the study was conducted. The processes by which the information was gathered, although variable across sites, provides an array of methods other researches can be guided by when attempting to evaluate their own services.

In spite of the limitations inherent in each of the studies in this systematic review of the literature, both quantitative and qualitative studies reviewed yielded similar findings. Biering (2010) in his own review of the literature, suggested that child and adolescent satisfaction appears to have at least three universal components; the patient therapist relationship, satisfaction with the environment in which the treatment is offered, and satisfaction around the outcome of the treatment in relation to positive changes in thought, feeling and skill development. These components, although also identified in this systematic review of the literature, have been expanded upon in a more thorough evaluation
and include perceptions around post discharge care. Inpatient treatment for young people provides them with a sense of containment which is often viewed in both positive (security) and negative (restrictive, unnatural) terms (Gill et al., 2016; Haynes et al., 2011), offering support whilst also instigating fears of blending in and coping when transitioning back to home.

For parents of hospitalised children with a mental illness, the findings from this systematic review of the literature are similar to other research; that consumer satisfaction is reportedly higher when there is positive parent-therapist interaction (Jakobsen & Severinsson, 2006; Scharer, 2002; Tarico et al., 1989), the child expresses satisfaction with the service, there is an absence of externalizing behaviours post discharge (Bjorngaard et al., 2008), there is a high perceived change in the symptoms that warranted admission (Blader, 2007; Brestan et al., 1999; Fontana et al., 2003; Kuehl et al., 1990), and the parents express a willingness to return to the service. For parents, ongoing concerns exist around being taken seriously and included in the treatment of their child (Stanbridge & Burbach, 2007). Stressors associated with having a child with mental illness prevail, with often perceived limited support and access to services (Hickman, 2014; Oruche et al., 2012).

**Directions for Future Research**

Ideally, in order to understand what aspects of a service design and delivery are satisfactory, consistent data collection methods are required. The small number of studies in this literature review yielded variability across all measures and suggests a need for further research that requires carefully conceived and executed investigations that take into consideration the need for methodological stringency. This is not to state however, that originality or site
specific evaluation yields poor quality results, or is irrelevant in the wider community. Rather, these features ensure that meaningfulness of results is preserved. Modification of existing standardised questionnaires to include aspects specific to a particular site, enhances reliability of scale if piloted and reviewed with a similar sample population first. The inclusion of longitudinal data collection also adds another layer to the results obtained. Future research may consider such inclusions.

**Conclusions and Implications**

Inpatient care is viewed as an often necessary treatment for mental illness in children and adolescents. Referring parties, young people and their carers, have experienced the positive benefits of this intervention, whilst highlighting areas warranting change or improvement. Although the methodologies applied in the studies in this systematic review are varied and with limitations, a consistent finding is the desire for respectful collaboration and inclusiveness between all consumer groups, in all areas of care and service provision. Identifying, designing and implementing methodologically rigorous research that can identify needs in service delivery on an ongoing basis, is warranted.
Table 4: Studies of consumer satisfaction with child and adolescent mental health services.

<table>
<thead>
<tr>
<th>Study</th>
<th>Method</th>
<th>Setting</th>
<th>Participants</th>
<th>Age</th>
<th>Aim</th>
<th>LOS</th>
<th>Outcome measures</th>
<th>Findings</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gowers et al. (1991)</td>
<td>Quantitative Survey questionnaire</td>
<td>Adolescent inpatient unit. Mix of inpatient, day-patient, outpatient, and consultation liaison.</td>
<td>148 Referrers</td>
<td>Not stated</td>
<td>Determine referrer’s satisfaction with the service and how they would use service again.</td>
<td>Not stated</td>
<td>Satisfaction with the service and intention to refer again. Why referrals had not occurred and in what circumstances the service might be used in the future. How important possible features of a psychiatric inpatient unit for adolescents are to referrers.</td>
<td>Child psychiatrists were the highest referral group with multiple referrals to the unit. Most frequent reason for referral was: “specialisation in the adolescent age range,” with most frequent disorders: “psychosis” and “eating disorder”. Referrer Satisfaction: Handling of past referrals, “completely or in the main satisfactory” No sig. difference between the professions. Minor dissatisfaction around understanding the nature of the services offered, or poor communication. Patient outcomes: On the whole “satisfactory,” with child psychiatrists most satisfied with patient outcomes compared to other professions. Re-Referral: Two-thirds of participants would refer again, with reason cited as need for inpatient treatment not available.</td>
<td>Authors did not state/identify limitations of their study. For one group of professions it was not stated how selection process occurred. Questionnaire not tested for reliability and validity. Date and time of study not reported.</td>
</tr>
<tr>
<td>Hellinger et al. (1996)</td>
<td><strong>Quantitative</strong> Satisfaction questionnaire (both parent and adolescent versions of each service specific module) Measures of Global Satisfaction: 5 items of the CSQ-8.</td>
<td>Two Outpatient and residential treatment settings including inpatient hospitalisation. One site offering traditional treatments plus case</td>
<td>984 families of children.</td>
<td>5-18.</td>
<td>Determine parental satisfaction regarding: a) intake assessment during the admission process to any setting, b) outpatient therapy.</td>
<td>At least one month treatment duration.</td>
<td>Client satisfaction reflecting: access and convenience of services, child’s treatment, parent services, family services, relationship with therapist, staff responsiveness, financial charges, discharge/transition services, and global satisfaction.</td>
<td><strong>Intake assessment</strong>: Parents significantly more satisfied with intake/assessment services at the Demonstration site in areas including: access and convenience of location, hours and scheduling, explanation and information in treatment plans, overall assessment, involvement in treatment plans, relationship with staff, wait between initial assessment and elsewhere – particularly for psychosis and anorexia. <strong>Past non users:</strong> Unfamiliar with the service or too far away. Would refer in the future for specialist inpatient care, particularly for psychosis. Of those who ‘definitely would not refer’, reason being: need to refer first to the district child and adolescent psychiatrist who “is in best position to make decision”. <strong>What participants value most in a service (desired improvements)</strong> Communication/liaison. Prompt response to crisis and emergencies, with access to inpatient beds. Ability to manage severe psychiatric illnesses.</td>
<td><strong>Strengths (as identified by authors)</strong> Developed own parent and child satisfaction scales. However, internal consistency assessed and found to be adequate to demonstrate reliability. Evaluation conducted by a team independent</td>
</tr>
<tr>
<td>Questionnaires mailed</td>
<td>Management; the other, case management not provided.</td>
<td>and c) residential treatment including inpatient care and that in residential treatment centres.</td>
<td>Allocation of services, financial aspects of care.</td>
<td></td>
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<tr>
<td>First wave parent questionnaire administered within 30 days of admission and treatment.</td>
<td>Satisfaction data from treatment modules collected every 6 months after child and parent had opportunity to experience treatment.</td>
<td></td>
<td>Satisfaction with treatment: Differences in inpatient services between the two sites not significant on all except issues around accessibility and cost.</td>
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<tr>
<td>For outpatient and residential patients: data collection at 6 months after take-up, and at 12 months.</td>
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<table>
<thead>
<tr>
<th>Ray et al. (1998)</th>
<th>Quantitative</th>
<th>Mental health facility providing consultation, inpatient, day, and outpatient services.</th>
<th>1252 (eligible participants rated by clinicians) of which 175 were inpatients, residential or day patients.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>Parental Satisfaction ratings (PSQ) over 4 year period.</td>
<td>3-18 overall age range across all sites.</td>
<td>To understand the factors influencing satisfaction in child and adolescent services.</td>
</tr>
<tr>
<td>Clinician Ratings: At episode conclusion (3 months since discharge, referred elsewhere or not seen</td>
<td>Inpatient: five day week (weekends at home)</td>
<td>Others can be referred to local services following Clinicians: To determine if goals of assessment/treatment substantially achieved.</td>
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<td>Clinician Ratings of outcomes: 69% rated as having had a positive outcome (this may include referral to another service)</td>
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<td>Inpatient and females 1.7 times as likely to be given negative</td>
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<td>Number of clinicians not stated.</td>
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<td>Both inpatient and outpatient treatments were included in episodes of care therefore clinician ratings are for overall service not</td>
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<tr>
<td>ratings as outpatients and males, respectively.</td>
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<td>Negative outcomes included: drop out, failure to improve, being forced to attend, family having unrealistic expectations, family requesting inpatient admission against recommendation, family being pressured to attend.</td>
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<tr>
<td>Patient identified by clinicians as not having shown improvement through treatment, most likely to be inpatients.</td>
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</table>

**Parental satisfaction**

Those that did not return the questionnaire more likely to have been rated by the clinician as having had a negative outcome.

No differences between inpatients and outpatients, although parents of inpatients felt that the service had met most or all of their family needs more often than parents of outpatients.

Clinical improvement main factor for clinicians when rating outcome among inpatients and by parents when rating satisfaction.

Other factors more prevalent for both clinicians and parents when rating outcome for outpatients.
<table>
<thead>
<tr>
<th><strong>Kaplan et al (2001)</strong></th>
<th><strong>Quantitative</strong></th>
<th><strong>Inpatient Child Psychiatric hospital.</strong></th>
<th><strong>166 patients. 111/166 parent/carers of the patients.</strong></th>
<th><strong>Mean age of patient: 12.8 years: Range 6-17.</strong></th>
<th><strong>Examined satisfaction with services among patients in a child and adolescent psychiatric hospital and their parents.</strong></th>
<th><strong>Mean LOS = 52.8 days</strong></th>
<th><strong>Overall satisfaction based on the following measures:</strong></th>
<th><strong>For all groups:</strong></th>
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<tbody>
<tr>
<td></td>
<td><strong>A four-section, 28 item questionnaire.</strong></td>
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<td><strong>Change in primary problem leading to admission.</strong></td>
<td><strong>High levels of satisfaction with services received.</strong></td>
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<tr>
<td></td>
<td>1st section: Overall evaluation of the extent to which the primary problem changed as a result of treatment.</td>
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<td></td>
<td><strong>Treatment experienced and other characteristics of the hospital.</strong></td>
<td><strong>A high degree of perceived change in the problem that led to hospitalisation, and</strong></td>
</tr>
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<td></td>
<td>In sections 2 and 3: Ratings around satisfaction with treatment/therapies, medications, activities, staff and the physical environment.</td>
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<td></td>
<td><strong>Abuse experienced/perceived.</strong></td>
<td><strong>A high likelihood of using the facility again.</strong></td>
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<td></td>
<td>Section 4: Yes or No format around drug use by staff or other patient.</td>
<td></td>
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<td><strong>Drug use.</strong></td>
<td><strong>Perceptions of abuse:</strong></td>
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<td><strong>Likelihood of return to the service.</strong></td>
<td><strong>21% of parents and 28% of children reported verbal or physical abuse from staff. Children reporting the abuse were also less likely to like the staff, and parents reporting abuse were less likely to return to the service again, and less likely to report satisfaction with staff.</strong></td>
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<td><strong>Problem improvement and likelihood of return:</strong></td>
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</table>
| Marriage et al. (2001) | **Quantitative Satisfaction Ratings at 3 time intervals** (admission, discharge and 4 months post return to community)  
CGAS ratings also provided by ward psychiatrist over course of inpatient stay.  
Parent completed Child Behavior Check list (CBCL).  
Youth completed Youth Self Report (YSR).  
Referring Clinician described 3 main problems prompting referral and also completed CGAS. | **10 bed Inpatient Psychiatric unit**  
72 adolescents' their carers, and the referring community clinicians. | **Mean: 14.6 years: Range, 11-18.**  
Determine the appropriate-ness of the services to participant’ needs. | **Mean LOS: 31.8 days: Range 9-58 days.**  
Patient's symptoms and functioning during inpatient stay  
Problems identified at admission  
Ward milieu and relationship with staff | **Patient Improvement:**  
Patients, parents and clinicians reported improvement in the adolescent’s global functioning and a decrease in symptoms.  
Ward psychiatrist at discharge rated 83% of the adolescents as having improved. Patients with psychosis or mood disorder showed greatest improvement.  
At 4 months post discharge referring clinicians reported 67% of patients as improved since admission. CBCL ratings at admission and 4 months post discharge saw parents reporting a decrease in total symptom score, while 65% of adolescents reported a decrease in overall symptom severity.  
**Consumer Identified Problems at Admission:** At discharge, 82% of parents and 76% of adolescents reported improvement in 1 or more of the three problems.  
At 4 months post discharge, 89% of the referring clinicians rated 1 or more problems as improved.  
**Correlates of Consumer satisfaction:**  
No significant correlation between symptomatic or functional improvement and satisfaction for any of the three groups. | Diagnoses were not derived on the basis of structured interviews, rather clinically based on multiple sources of data recorded in case files.  
Multiple community-based clinicians gave CGAS ratings of patients. Interrater reliability cannot be confirmed.  
A number of the questionnaires created were in response to service specific needs and psychometric properties have not been properly explored.  
**Strengths**  
Inclusion of all significant consumer groups in providing a “whole picture approach” to the experience of hospitalisation of the young person. |
<table>
<thead>
<tr>
<th>Comments</th>
<th>Description</th>
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<tbody>
<tr>
<td>For all groups: significant correlation between helpfulness of discharge recommendations and overall satisfaction with the program.</td>
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<tr>
<td>Positive comments around service delivery:</td>
<td></td>
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<tr>
<td>Patients:</td>
<td>Dr helpful in understanding problems; availability of nurses to talk to.</td>
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<tr>
<td>Negative Comments:</td>
<td>Harsh discipline; lack of privacy.</td>
</tr>
<tr>
<td>Both parents and children viewed the ward as having inflexible scheduling and some found the containment aspect of the ward, restrictive.</td>
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<tr>
<td>Suggestions for improvement:</td>
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<tr>
<td>Staff interaction (more polite); improved continuity of care (same team members looking after them).</td>
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<td>Parents requested additional discharge planning support during transition back to community.</td>
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<tr>
<td>Referrers also requesting improved discharge planning and post discharge management.</td>
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<tr>
<td>Blader et al. (2007)</td>
<td><strong>Quantitative</strong></td>
</tr>
<tr>
<td>Tas et al. (2010)</td>
<td>Quantitative</td>
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</table>

Clinic rating of progress on individual psychopathology and family functioning compared with self-ratings by patients and their carers.
| Geraghty et al. (2011). Australia | Qualitative: Content analysis of 26 consultancies provided over a two year period. Inpatient: Child and Youth acute mental health inpatient unit. 50 parents/carers. 0–17. To investigate how parents have utilised a consumer consultant support service provided in a mental health unit. 12-13 days. Identify themes in the records of consultation provided by consumers to parents of children admitted in an attempt to better understand how parents utilise peer support when it is offered to them. Four Broad domains identified: Experience of service directly or indirectly associated with the admission. Negative experiences reported twice as often as positive experiences: Concerns around the ward being unsafe and untherapeutic, with critical and unresponsive staff. Unavailability of services also criticised. Positive experiences reported the reverse. The consultancy service itself viewed positively. Emotional response to their child’s admission. Distress often voiced around having a child in a mental health inpatient unit. Guilt, blame, worry and anxiety often cited. Coping with challenges associated with the admission. Admission perceived as very disruptive with other family members being affected equally. Isolation from other family and supports whilst tending to needs of the child in hospital also reported. Need for information. More information requested around the child’s mental illness. Data is derived solely from sessional records written by members of the consultancy team. Actual interviews or verbatim statements made by parents/carers may have provided different or additional information. |
| Biering and Jensen (2011) | Qualitative Hermeneutic study Interviews (check list guide) Conducted 2-3 months post discharge. Patient able to select their own interviewer from a list of nurses and counsellors working on the ward. | Inpatient psychiatric unit. | 14 adolescents | 14-17 To identify elements of the services and treatment offered that contribute to satisfaction AND To identify how adolescents describe and understand satisfying treatment outcomes. | 6 weeks to 5 months. Mean = 2-3 months. Adolescent’s satisfaction or dissatisfaction, AND Adolescents’ description and comprehension around satisfying treatment outcomes. | 13 concepts related to satisfaction identified: 1. Secure Place (Feelings of shelter and trust expressed towards staff). 2. Isolation from outside world: Sense of loss of connection with family, friends, school. This likely to affect desire to return to services 3. Activity: Having little to do found to be unsatisfactory. 4. Tough Love and Discipline: Adolescents perceived being forced to engage in activities others acknowledged as good for them which they did not wish to engage in but recognised as beneficial in the long run. 5. Peer solidarity: Satisfaction expressed in meeting with others with similar problems and needs. 6. Self-expression: Satisfaction expressed around being able to discuss their feelings and experiences with peers and caregivers. 7. A person not a patient: Preference for staff to treat them as individuals and not patients. 8. Consideration: Satisfaction reported when adolescent perceived staff as treating them in a considerate and compassionate manner, particularly during times of vulnerability. 9. Satisfying treatment outcomes: Included improved mental health, personal... | Unable to determine whether selecting own interviewer influenced the responses provided by the participants. Interview guide can be interpreted as leading the discussion and not allowing sufficient opportunity for participant to have his or her own self-directed narrative around the experience of the admission. |
| Haynes et al. (2011) UK | Qualitative Grounded theory | Inpatient 1 NHS adolescent inpatient unit and 1 adolescent unit at an independent hospital in the United Kingdom. N = 10 Young people Resident Inpatient for at least 2 weeks in the last 18 months. 13-19 | 4 weeks to 36 months | Subjective views of psychiatric inpatient care. | development and the healing of the self.  
10. Improved mental health: (feeling better as a consequence of the treatment received).  
11. Personal development: (Overcoming problems, finding hope).  
12. Healing the self: (Self-esteem).  
13. Improved family relations: (Included being better understood by parents). |

**Core category:**  
Living in an “alternate reality” (feeling different, restricted and disconnected; fearful confused)  
**Contributory Categories:**  
Feeling restricted (Boredom, annoyance. Loss of freedom, constantly observed)  
Feeling disconnected (from family, friends, school).  
Negotiating new relationships (with staff and other patients)  
**Outcome Categories:**  
*Developing supportive relationships* (with other young patients).  
*Recreating reality* (trying to participate in normal activities).  
*Intellectualizing* (normalizing, rationalizing, looking forward and thinking positively).  
*Avoiding harm* (Avoidance in coping with violence and aggression witnessed on the ward).  
**Conclusion:** Psychiatric hospitalisation can cause strong affective reactions and may affect identity and self-esteem.  

Two different units assessed but without clarification of differences in experiences and treatments offered.  
Age range very broad across different developmental levels.  
Time between inpatient discharge and interview not specified. Recall may have been affected.  
2/10 participants were outpatients the time of the investigation which may have affected their perceptions around care.
| Oruche et al. (2012) U.S. | Qualitative descriptive design | Multiple sites including inpatient. | 20 carers (all female) | Aim: To identify what caregivers of children with diverse mental health needs say they need to help them improve their personal well-being. | Service needs | Five major themes: |

**Struggling with care systems:** Range of barriers to obtaining sufficient help for their children, including location, red tape, limited finances, inadequate assistance during crisis, being blamed for child's illness.

**Living in fear:** (Dangerous nature of child’s illness).

**Being Burdened and exhausted:** Anxiety, exhaustion and stress of meeting the child’s needs.

**Worrying about the rest of the family:** Worried about the well-being of other members of the family.

**Having good things happen sometimes:** Gratitude for positive events and outcomes, experiencing kindness from others including staff and other professionals, and receiving support from other families with similar experiences.

Self-referred with a paid $40 incentive, the latter of which may have contributed to willingness to participate.

All female participants.

Diversity of age ranges of the children along with different developmental needs.

Vastly different levels of acuity requiring different interventions.

Nature of mental health services not specified.

Total time spent in receipt of mental health services not stated.

Ethnic minorities poorly represented.

Group sizes varied considerably with no explanation of how groups were designed/came together. One “group” had only one participant.

All participants from one general area, may not be representative of the whole of the state.
<p>| Richardson et al. (2013) Australia | Qualitative Inductive thematic analysis. In-depth semi-structured interviews examining parents' current reaction to having a youth with a mental illness, as well as their initial response. Questions also focused on parental perceived social support and coping, experience of stigma and perceived quality of accessed care. Also requested to share ideas around the types of support required to assist in coping with their child's illness. | CAMHS Including an inpatient unit, partial hospitalisation program, and community clinics. | 15 Caregivers Self-referred | Young people 8-18 years. Mean: 13.96 years. | Aim: To explore the loss and grief of a representative sample of parents engaged with a CAMHS (youth has major psychopathology). To identify the therapeutic needs of parents and family members over the course of their youths' mental health care. | Youth had been engaged with the service for an average of 3.5 years (range 7.3 months–11.3 years). Occasions of service ranged from six to 341 (median number of occasions = 43). Six youth had been in hospital at least once in relation to psychopathology. | Cognitive, behavioural and emotional experiences around having a child with mental illness. | Levels of parental support and coping. Experience of stigma. | Perceived quality of care. | 6 Overarching themes identified: Parents' narrative of finding out: Worry and concern for the future, but relief knowing that there was an explanation to what they had been observing/experiencing. Profound and pervasive loss: Loss of their 'real child'; dashed expectations, uncertainty regarding the future loss of parental confidence and sense of control. Complex grief: Strong sense of loss and grief - often ambiguous and non-finite. Waning support: Feelings of isolation from support groups, particularly among single parents, perceived lack of support from professionals involved in child's treatment, hiding their child's illness from others in order to reduce risk around isolation/rejection from others/being judged. The challenges of caregiving: Looking after child's needs as well as their own and that of other family members. Call for assistance: Empathical professional support crucial, education around the problem, prognosis and expectations. Opportunities to talk and self-reflect. | Small sample size over many different treatment settings. Mainly mothers therefore unable to generalise to other carers of different gender/status. No exclusion criteria. The diagnoses varied considerably therefore unable to ascertain the role the child's diagnosis played in parental loss and grief. Self-recruitment via flyers and word of mouth. Cannot make inferences around those who did not wish to participate. Only 15 participated with no exclusion criteria, until saturation reached. However authors reported a desire for a representative group of participants reflecting demographic characteristics of the patients using the service. Was some form of purposeful sampling utilised? Participant selection unclear. |</p>
<table>
<thead>
<tr>
<th>Salamone-Violi et al. (2015)</th>
<th>Qualitative</th>
<th>Inpatient</th>
<th>11 young people</th>
<th>Aim: Identify and understand the experience of young people admitted to a psychiatric inpatient unit.</th>
<th>4-15 days.</th>
<th>Identify aspects of the inpatient experience the young person found satisfactory or not.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>Thematic analysis</td>
<td>Child and adolescent psychiatric inpatient unit.</td>
<td>Purposeful sampling technique.</td>
<td>15-17 years of age</td>
<td>Three Overarching Themes:</td>
<td>Emotional Response to the Inpatient Experience: Varied depending on whether the admission was considered necessary. Subthemes included acceptance, a sense of powerlessness, and fear of the unknown.</td>
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<td></td>
<td>Semi-structured interviews.</td>
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<td>Experience of the Admission itself: Influenced by relationships young people had with other staff, the physical environment of the ward and the type of therapy received. Satisfaction more likely experienced if the relationship with staff perceived as supportive, and therapy focus was on family meetings that resulted in a better understanding around the difficulties and needs of the young person. Overall dissatisfaction with the physical layout of the ward and in particular, the lack of access to an outside area.</td>
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<td>Outcomes: Containment that the inpatient unit provided deemed on the whole satisfactory. Some individuals not in favour of admission, viewed containment in negative terms. Admission perceived as an opportunity for staff to advocate and provide support around child’s needs, and therefore viewed positively. A change in mental state to that of greater optimism was reported.</td>
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<td>Exclusion of non-English speaking patients.</td>
<td>The very unwell excluded from participation.</td>
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<td>No generalizations of results can be made about excluded participants.</td>
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<td>No comparison between inpatients with those that have never experienced an inpatient admission or those who have had previous admissions.</td>
</tr>
<tr>
<td>Gill et al (2016)</td>
<td>Qualitative</td>
<td>Inpatient Unit A: Therapeutic environment and longer admissions (3 months average stay). Units B &amp; C offered more crisis-led services with shorter lengths of stay (1 month average stay).</td>
<td>N=12 Adolescents</td>
<td>Mean: 16 years 3 months. Range, 13-18.</td>
<td>Aim: Extend previous research by focusing not only on adolescent perceptions of the benefits and drawbacks of psychiatric inpatient care, but on their expectation about the transition back home.</td>
<td>Mean length of stay &lt; 3.5 months.</td>
</tr>
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</table>
CHAPTER 3
WHAT ABOUT THE RISK? REFERRAL AND ADMISSION TO A CHILD AND ADOLESCENT PSYCHIATRIC INPATIENT UNIT: THE REFERRERS’ PERSPECTIVE

Status of paper: “Text in manuscript”

Authors:
Gigetta ML Salamone-Violi, Anna Chur-Hansen, and Helen Winefield
## Statement of Authorship

<table>
<thead>
<tr>
<th>Title of Paper</th>
<th><em>What about the risk?</em> Referral and admission to a child and adolescent psychiatric inpatient unit: The referrers’ perspective</th>
</tr>
</thead>
</table>
| Publication Status | - Published  
- Accepted for Publication  
- Submitted for Publication  
☑ Unpublished and Unsubmitted work written in manuscript style |
| Publication Details | |

### Principal Author

<table>
<thead>
<tr>
<th>Name of Principal Author (Candidate)</th>
<th>Gigetta Maria Luigia Salamone-Violi</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contribution to the Paper</td>
<td>I was responsible for the conception of the research upon which this paper is based. I produced the first draft of the manuscript and will submit the final manuscript. I completed the literature search, data collection and data analysis. As the primary author I will be in contact with the journal and will be responsible for responding to reviewers and editors based on prior discussion with and consent from ACH and HW.</td>
</tr>
<tr>
<td>Overall percentage (%)</td>
<td>85%</td>
</tr>
</tbody>
</table>

Certification: This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.

Signature |  
Date | 15/11/16 |
Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

<table>
<thead>
<tr>
<th>Name of Co-Author</th>
<th>Professor Anna Chur-Hansen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contribution to the Paper</td>
<td>Assisted in the initial stages of conceptualization of the research, and refined and critically analysed the drafts, which included making suggestions and providing editorial input. Checked the interview transcripts for accuracy and participated in the coding of one interview and checked final coding, to ensure consistency of findings.</td>
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<th>Signature</th>
<th>Date</th>
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<td>2023</td>
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<tr>
<th>Name of Co-Author</th>
<th>Professor Helen Winefield</th>
</tr>
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<td>Contribution to the Paper</td>
<td>Assisted in the initial stages of conceptualization of the research, and refined and critically analysed the drafts, which included making suggestions and providing editorial input. Checked the interview transcripts for accuracy and participated in the coding of one interview and checked final coding, to ensure consistency of findings.</td>
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<td>2023</td>
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Abstract

The inpatient unit has an important role in the treatment of young people and adolescents suffering from mental illness. However, there is limited research regarding the effectiveness of the admission process from the perspective of the consumer groups who access it. This study was designed to identify the perceptions around referral and admission to a psychiatric inpatient facility for children and adolescents in a major capital city in Australia.

The qualitative study utilised in-depth semi-structured interviews with nine clinicians of varying disciplines employed across child and adolescent mental health services. Thematic analysis of the results was applied.

Safety and management of risk was identified as the overall theme and driving force behind referral to the inpatient unit, with participants perceiving the referral process as at times difficult and inconsistent. Perceived lack of specialist and diverse therapeutic interventions available within the inpatient unit, along with inconsistent and at times short length of stay, and incomplete or poorly designed discharge, was perceived as potentially compromising patient care and well-being.

Lack of alternative community-based resources has led to a potential over reliance on the inpatient unit by referrers whose primary aim is the safety and well-being of young people under their care. The challenge to both inpatient and community-based services, nurses and other mental health professionals, is how to adapt and modify their service delivery in order to work collaboratively in engaging and maintaining in treatment young people with mental illness in need of care.

Key words: Child and adolescent, inpatient, psychiatric, qualitative, referrers, service delivery
What is Already Known on this Topic

1. Mental illness among young people has been found to peak during the teenage years and emphasis is placed on early intervention and providing care in the least restrictive environment, that is, through community based supports.

2. The initial contact young people and their carers have with mental health services is likely to influence all future contact, with many young people failing to continue in care as a consequence of negative experience or failure in having expectations around care met.

3. Hospitalisation although warranted in some circumstances, does not necessarily result in transferability of skills and continuity in treatment post discharge.

What this Paper Adds

1. An understanding of the complex process of keeping a young person with mental illness and escalating risk, managed within a community setting.

2. Perspectives from referrers around aspects of care that are likely to engage and maintain connection to services with the young person.

3. Considerations for future models of care to include additional services within the community to cater for the diversity, depth and breadth of mental illness from which young people suffer.
Introduction

Each year in Australia, up to 14% of children and adolescents aged between 0-17, experiences mental health problems (ABS, 2008). With mental illness shown to peak during the teenage years with potentially devastating mental and physical health consequences (Fichter, Kohlbueck, Quadflieg, Wyschkon, & Esser, 2009; Needham, 2008; Vida et al., 2009), appropriate early intervention is essential.

In young people who experience mental health problems, most of the disorders are relatively short lived and emphasis is placed on treatment being provided through community-based services, with the expectation that these services and the family will provide the necessary support (Clinton, Lunney, Edwards, Weir, & Barr, 1998; Jubb & Stanley, 2002; Kent & Yellowlees, 1994). A further expectation is that the community-based teams are staffed by multi-disciplinary professionals, including mental health trained nursing staff, skilled to provide a range of services that will cater to the diverse needs of young people with mental illness, and that additional supports, both government and non-government, are available and accessible to the clinician in the provision of care.

There will be occasion when the young person experiencing mental health difficulties requires intervention and containment beyond that which the community team and community-based agencies can provide. In the absence of suitable alternatives, referral and admission to a psychiatric inpatient unit occurs.

Containment offered by an inpatient unit can provide stabilization and rapid reduction of symptoms and risk (Lamb, 2009), particularly for those individuals suffering from severe illnesses (Raphael, 2000) such as psychosis, severe disorders of depression or anxiety, as well as a range of conditions with
co-morbidity (Mathai & Bourne, 2009). Other factors around which admission are considered include suicidal behaviour or ideation (Gutterman, Markowitz, Laconte, & Beier, 1993), outpatient treatment failure, or crisis stabilization (Hopkins, Loeb, & Fick, 2009). Assessment related to diagnostic issues (Moses, 2010), severe family dysfunction, specialist treatment/ intervention, and reduced parental capacity to contain the child or manage the level of risk (Golubchick, Server, Finzi-Dottan, Kosov, & Weizman, 2013), is also considered reason for inpatient admission.

As the initial contact with the inpatient service can influence all further engagement (Clarke & Winsor, 2010), the process of admission should aim to be an appropriate, effective and satisfactory experience. This includes ensuring that initial expectations are met (Clinton et al., 1998; Hopkins et al., 2009; Jubb & Stanley, 2002), or at least that the discrepancy between expectations and experiences is minimal. Understanding what referrers believe to be important in providing care is one initial step towards attempting to identify appropriate and adequate management of young people with mental health problems.

There are very few recent studies that have examined referrers’ expectations and satisfaction with referral and admission of young people to psychiatric inpatient units. Early studies involved surveys related to treatment and environment (Chung, Pardeck, & Murphy, 1995; Gowers, Crisp, Joughin, & Bhat, 1991; Marriage, Petrie, & Worling, 2001; Steinberg, 1994; Wells, 1989). Dissatisfaction with the referral process was reported around the practice of reassessment by the receiving unit in order to confirm diagnosis and clarify goals, which had the potential to delay admission (Corrigall & Mitchell, 2002; Steinberg, as cited in Rutter, Taylor, & Hersov, 1994; Wells, 1989). Similarly,
perceived inadequate lengths of stay, lack of or inadequate treatment, and poorly defined discharge and management plans, were perceived by referrers as poor use of the inpatient experience (Chung et al., 1995). When referrer expectations were met however, level of satisfaction with the referral process increased. Meeting referrers' needs was interpreted to mean that the goals for which referral were set, had been met. A question one may need to ask however is: in meeting the referrer's goals or needs, does the young person receive the best care available to them in the most appropriate environment?

This study examines the perceptions of referrers to a child and adolescent psychiatric inpatient unit regarding expectations and experiences of the referral and admission process. A qualitative approach was selected in order to enhance the extent and depth of information that can be derived beyond the scope of survey results that can limit or bias answers by the wording of standardised questions. This study adds to the limited body of research around the referral and admission process of young people to a psychiatric inpatient facility. Furthermore, it sets the path for research with the other consumer groups in order to identify the nature of care that best meets the needs of the young person and has the potential to ensure continuity of care. The research question that guided the study was: “What have been referrers’ experiences around referral and admission of children and young people to a psychiatric inpatient unit?”

The inpatient unit in this study is the only designated 12 bed psychiatric inpatient facility for children and adolescents in a major capital city in Australia, and provides specialised care and support for children and adolescents with severe mental health problems including psychosis, depression, suicidal ideation and intent, or who have complex and coexisting disorders that may require
multiple assessments and specialised care. The inpatient unit experiences up to 500 admissions per year.

Referrers in this study include clinicians from community-based, government funded, child and adolescent mental health clinics. Nursing and allied health clinicians (psychology, social work, occupational therapy) make up the majority of staff in community-based mental health clinics in the state in which this study was undertaken and are responsible for case management and therapy. Support from psychiatry is often limited to one full time equivalent staff member per team.

Methodology

Approval was sought and received from the appropriate Human Research Ethics Committee.

Recruitment

A purposeful sampling technique recruited participants from varying professional backgrounds working within child and adolescent community mental health teams. Prior to commencement of the study, an email outlining the nature and the purpose of the study was sent to each of the teams throughout the state in which the study was conducted. Potential respondents were included in the study only if the interviewer had no current working relationship of shared care of any young person referred to the inpatient unit. As the bulk of the referrals into the inpatient unit are either referred by government funded community-based child and adolescent mental health teams, or discharged to same for post discharge follow-up, only mental health clinicians from these settings were included in this study. Staff from within the psychiatric inpatient unit under review in this study was excluded from participation.
Clinicians willing to participate in the study were asked to send a confirmation email back to the lead investigator (the first author and clinical psychologist in the inpatient unit). As emails signalling intent to participate were received, details (name, profession, and team) were recorded on a participant list, in the order in which they were received. Participants were selected from the list, in the order in which they appeared. Purposeful sampling occurred in order to achieve a representation of professions across the state. Where two nurses were listed, the first to respond was selected. This was the same process for each of the professions, as well as the teams from which the participants originated. The objective of purposeful sampling, is to select information-rich cases for the most effective use of resources (Palinkas et al., 2013). The selection of cases with maximum variation (different professional groups, different teams) was undertaken for documenting unique experiences that emerged in accessing the child and adolescent mental health unit in the state in which this study was undertaken. A purposeful sampling approach can be used to identify important common patterns that cut across variations (Duan, Bhaumik, Palinkas, & Hoagwood, 2015).

**Procedure**

**Consent.**

Potential participants were provided with standardised information sheets (Appendix 1.1) prior to being asked to give their written consent for participation in the study (Appendix 1.2). Written consent was obtained on the day of the interview.
Participants.

Nine clinicians participated in the study, four women and five men. Three clinicians were working on a part-time basis. Years of practice in child and adolescent mental health ranged from 3-30 years, with an average of 20.5 years. Their disciplines were nursing, psychiatry, psychology, social work, and occupational therapy.

Data Collection.

Interviews were conducted at a location suitable to the interviewee. They included an office outside the psychiatric inpatient unit targeted in this study, or at the employment site of the participant. Open-ended semi-structured interviews, ranging from 28 minutes to 1 hour and 49 minutes (average 58 minutes) were conducted and audiotaped with participant consent, before transcription by the interviewer. All interviewees were aware of the interviewer’s position on the inpatient unit as a clinical psychologist, and reassurance regarding anonymity was repeated at time of consent and at the beginning of the interview.

Each interview commenced with the broad question: “Can you tell me about your experiences in referring young people under your care to the inpatient unit?” Additional interview questions were guided by the interviewee’s responses and were also complemented by previous participants’ responses. An audit trail was kept during data collection and data analysis. The audit trail guided the decision to end sampling when data saturation was reached, that is, the point at which collected data are repetitive and are not providing new information (Morse, 1995).
Data Analysis.

Interview data were analysed thematically following the guidelines of Braun and Clarke (2006; 2013). This method of analysis involves the identification of themes within and between participants’ transcribed interview data. The six stages of thematic analysis (Braun & Clarke, 2006; 2013) were applied. Emerging themes were defined and redefined by all authors until the main themes were established.

Checking of the themes by both the second and third authors enhanced methodological rigour and trustworthiness (Tracy, 2010). Participant validation of the transcripts was attempted, with five respondents requesting a viewing of their transcripts. One participant requested to add additional information. A second respondent made grammatical changes to the text in order to improve readability, whilst the remaining three made no changes.

Results

In all, the overarching theme to emerge was around “Safety and management of risk”. Three subthemes under the main theme included “Admission criteria”, “Access to therapy”, and “Referrer anxiety”. Within these subthemes, there appeared to be two categories of participants:

The first category included participants who did not experience dissatisfaction with admission and referral to the inpatient unit, in spite of identifying aspects that they found challenging or difficult, “I really can’t think of admissions I have asked to be in the ward that have been inappropriate. That’s including from the initial triage with the nurse, the admission to (the inpatient unit) and the referral back to us in the community. It has been significantly beneficial” (P7, Psychiatry 2).
The second category of participants reported a perception of the inpatient unit as undermining the community team clinicians’ ability to determine suitability for admission. “...it almost gives the impression that if you are working in the community, you have a lesser level of knowledge because you are not dealing with the very complex patients” (P3, Nursing). This category of participants also expressed an expectation that the inpatient unit should be available to the community in a supportive role and therefore not question referrals made, “my opinion is that an inpatient facility should work for the community, rather than the other way around” (P4, Allied Health). The differences in expectations of the inpatient unit by referrers appeared differentiated on perceived need for biomedical versus psychosocial intervention and support.

**Admission Criteria**

Participants from both categories in this study acknowledged that referral of young people presenting with depression, psychosis and those who are in acute states of distress with active suicidal ideation and self-harm, are rarely questioned by the inpatient unit, particularly when the referral came from psychiatrists. “... They are generally straightforward, they are clearly unwell, and there is not going to be much push back from the ward about taking someone like that” (P4, Medical).

Participants perceived the inpatient unit’s willingness to accept referrals from nursing and allied health staff requesting psychosocial intervention and support for their patient, as more likely to be challenged. However, all professional categories acknowledged a perception that the inpatient unit did not view a request for respite as a high priority for admission to the unit. “I don’t
know whether the (inpatient unit) sees itself in that sense. I think it is a safe place to go for a while if support systems are falling apart ... that’s giving the support system i.e. the carers a rest. You know if I was trying to bring that one up (as) part of the admission hypothesis or goal, I wouldn’t say that to anyone on the ward because I don’t think that fits with their idea of what they do” (P5, Allied Health).

Many of the participants perceived the language content used by referrers in seeking admission, as influencing the inpatient unit’s willingness to consider the referral. Language content included specific issues that the young person was experiencing (medical, social, environmental) and that could not be addressed in a community setting. For example, participants who expressed little difficulty in admitting to the inpatient unit reported providing a more detailed referral, outlining existing and potential escalation of risk factors, as well as detailing previous attempts at addressing, managing and maintaining the mental health issues for which they were now seeking additional support from the inpatient unit.

“I’ve always been careful about the way I present the situation and I present it in a psychiatric way..., we have multi-disciplinary teams and generally speaking social workers don’t speak about mental health issues in a psychiatric way. I have always encouraged when speaking to another staff member, if I think yes they need admission, I say this is the way that you need to present this, you have to speak the language otherwise they are not going to hear you” (P9, Nursing).

Access to Therapy

Participants perceived the inpatient unit to have little understanding of the difficulties in maintaining safety and providing care for the young person in the
community, where availability and access to resources was a difficult process, complicated by family dynamics, interventions that are not always available, specialist services that are limited, cannot be accessed or do not exist, as well as difficult patient-therapist relationships that result in poor rapport and lead to disconnection from services. "It's a completely different environment, a community is a dynamic environment where there's all those unknowns that are going on out there, the chaotic systems the young people have to deal with: their families, their friends, their peers, yeah it just makes it a completely different ballgame" (P4, Allied Health). Expectations of care and support from the inpatient unit therefore, were influenced by the community clinicians’ ability to access alternative services.

Medical and psychiatric participants who reported specific expectations of the inpatient admission, such as providing a second opinion around assessment or medication, perceived the intervention they received from the inpatient unit as meeting their needs. "I can't really see how I would like to see it changed, no I'm happy with what (the inpatient unit) provide." (P7, Psychiatry). Participants, particularly those from nursing and allied health backgrounds responsible for providing psychological based therapies and interventions, and who desired additional support from the inpatient unit in instigating and providing specific therapy based intervention, were more likely to voice disappointment with the referral and admission process. This was evidenced through the subthemes, Length of stay and Lack of structured therapies/group programs.
Length of stay.

The perceived needs of non-medical participants appeared centred on opportunities for therapy based interventions beyond that of pharmacological intervention, finding perceived early discharge of the young people they referred unhelpful on multiple levels. “...I’m saying that it has to be long enough for something to have been worked out or changed, like a better or different management plan” (P 6, Nursing).

Lack of structured therapies/group programs. They also reported the perceived lack of structured therapist-lead groups or other therapies, a poor utilization of the inpatient experience, particularly around the difficult to engage young person. “It wouldn’t hurt these kids to be exposed to that sort of stuff and then that creates a structure within our environment within the ward which makes it less about being bored, getting into trouble, bouncing off each other, sitting around watching movies. They might learn something that helps them later. I just feel like a little bit of structure would be useful” (P 2, Allied Health).

Referrer Anxiety

Concerns around risk management and carrying risk, particularly among the junior or less experienced community staff (regardless of discipline), was a driving force around referral to the inpatient unit. This was the greatest source of concern when referral was not accepted. “The other thing is risk, you know I don’t worry as much as some of the junior staff about carrying risk but it is an awful feeling knowing that you have to make a decision one day about how safe it is for the client and hope that lasts until the next time you see them” (P5, Nursing).
There was acknowledgement by participants that risk management alone was not a reason for inpatient referral, with clinicians needing to look toward their own team for managing risk in the community. "I think some other teams might see it as a place for their client to be safe and they don’t have to worry but that shouldn’t be the inpatient role; you should be able your manage your risk in the community unless it’s really acute" (P4, Allied Health). Some participants viewed the inpatient unit as an extension of their team however and therefore expressed the belief that requests for additional support should not be challenged.

**Discussion**

Current research suggests that the relationship between consumer satisfaction and service quality and delivery is not always clear (Gill & White, 2009). Meeting individual needs and expectations appear more positively related to overall satisfaction, and this appeared to be supported by the findings from this study. Participants identified psychosocial circumstances in which they perceived effective and safe management of children and young people suffering from mental health problems, that cannot be achieved “in the least restrictive environment”, that is, the community. When assistance has been perceived as questioned or not forthcoming, satisfaction with the referral and admission process was reduced. These circumstances were described within basic themes around “Admission criteria”, “Access to therapy” and, “Referrer anxiety”.

There was general consensus amongst participants that referrals of individuals with severe mental health problems, and those in acute crisis, were rarely challenged. This finding is in line with research that identifies these same conditions as valid indicators for hospital admission (Golubchick et al., 2013; Gutterman, Markowitz, Laconte, & Beier, 1993; Lamb, 2009; Mathai & Bourne
2009). However, participants in this study have stated that the inpatient unit often challenges other equally complex case presentations. These cases usually involve changes to psychosocial circumstances, and referral is often interpreted as a need for respite and therefore not a priority.

A 12-bed inpatient unit that operates as a state-wide service and is the only inpatient unit for children and adolescents suffering mental health problems is unlikely to meet the needs of all potential consumers. The reliance on the inpatient unit to fill the gap in alternative community-based services remains however, and raises a number of problems that will in turn affect the wellbeing and recovery of the young person in need. For example, if supports are not available in the community when referral is made, what happens when the inpatient admission concludes and psychosocial circumstances that led the young person to hospital remain unchanged? Participants presented a perception that extending length of stay was a possible solution to young people learning skills, through intensive and individualised therapy, in order to assist them with the challenges of living within the community. The background of past research however, suggests optimal lengths of stay are difficult to determine (Green, 2007) and that skills gained within inpatient facilities are rarely maintained post discharge (Gowers & Rowlands, 2005; Hanssen-Bauer et al., 2011). This “solution” is weak. This is not to say that skill training and other forms of intervention should not be attempted. The question remains as to whether the inpatient unit is the best place to instigate such intervention, or if a collaborative approach with community teams is a more appropriate alternative.

Community teams are multidisciplinary. The case management model within these teams often restricts the amount of time clinicians can dedicate to
specialised program delivery. However, mental health nurses, psychologists and other mental health professionals have the skills and the expertise to offer programs that may benefit the young person, as well as keep them engaged in therapy. Similarly, day programs run by the inpatient unit in collaboration with community-based clinicians, may address the issue of skill transferability as well as continuity in treatment provision.

In highlighting difficulties in providing community-based care, participants in this study refer to the “difficult to engage” young person, suggesting that hospitalisation provides an opportunity to engage with and commence therapy. Although such a solution may be warranted in some circumstances, intensive home-based therapy may be another possible alternative warranting consideration. This is an approach that has been used successfully in Child and Adolescent Mental Health Services (CAMHS) in other states in Australia. In the state in which this study was undertaken however, community-based mental health clinicians have limited capacity to be mobile. Young people with mental health problems who do not seek assistance run the risk of their condition deteriorating to the point of requiring involuntary detention and therefore hospitalisation – a far from satisfactory outcome for all parties concerned. A mobile approach in service delivery may reduce the likelihood of such an outcome for this group of young people.

Referral for admission to the inpatient unit was the preferred option for the participants in this study around the issue of safety. Safety is often a serious concern, with both the ‘difficult to engage’ as well as ‘high risk’ presentations and understandably comes with high levels of anxiety experienced by the young person themselves, their family as well as the treating therapist. Whereas
participants in this study acknowledged that referrer anxiety around managing risk alone is not sufficient grounds for referral of the young person to the inpatient unit, it certainly becomes a driving force.

Hospitalisation provides containment, not only physical containment but containment of the anxieties everyone experiences when attempting to care for young people who are actively suicidal or engage in dangerous, life-threatening self-harm. Containment under such circumstances is an appropriate request (Lamb, 2009). The question needs to be asked however: if suicidal and other safety issues become chronic or recurring, is hospitalisation the most appropriate treatment option or does it encourage a dependence that makes transitioning back to the community difficult to achieve? The high-risk scenario is one that best exemplifies the need for both community and inpatient services to work collaboratively and in a flexible manner. The exploration of all alternatives is essential in determining the best form of intervention and environment in which to provide the necessary care. An “either” (hospitalisation) “or” (community-based) approach to caring for the high-risk patient, has proven an unsatisfactory approach for participants in this study. Previous research on child and adolescent perceptions of psychiatric inpatient care as well as carer satisfaction with inpatient care (Marriage et al., 2001; Oruche, Gerkensmeyer, Stephan, Wheeler, & Hanna, 2012; Richardson, Cobham, McDermott, & Murray, 2013) identified a desire for a more collaborative approach amongst consumers, clinicians and treatment environments. Ongoing support and active involvement in inpatient as well as post discharge planning was considered highly desirable.

The care of young people is the responsibility of the whole community and models of care require clear pathways with appropriate services and access
to them in order to keep the young person engaged in therapy, as well as
minimise the long-term impact of mental illness on their lives. This study has
highlighted the difficulties some community-based clinicians face in managing
young people with complex mental health problems. Lack of alternative safe
environments, particularly when family supports are no longer feasible,
contributes to frustration with the inpatient unit when referral is challenged or
rejected. Resources around provision of alternative care, such as day programs,
outpatient groups and changes to the way in which community-based services
operate, to include a more mobile approach, may be possible contributions to
maintaining ongoing and regular assessment and support for young people whose
level of risk is difficult to determine, or escalates. Currently group programs
such as those specifically designed for young people suffering from psychosis,
eating disorders, and anxiety disorders are operational to some degree in most
Australian states and are heavily utilised. Adolescent day programmes offering
group and individual therapy and assertive mobile services however in the state
in which this study was undertaken are limited, have been scaled down or non-
existent. This gap in service delivery contributes heavily to the dissatisfaction
experienced by referrers and other service providers.

This study’s strengths include the contribution it has made to the limited
body of research around the referral process of young people to psychiatric
inpatient facilities. It has demonstrated the benefits of qualitative research in
identifying additional and specific information around the difficulties faced by
community teams in providing care to young people with mental health needs in
a safe environment. It has highlighted the need for collaborative care between
inpatient and community-based services and the need to reconsider changes or modifications to service delivery.

A limitation of this study is the emphasis on “one voice” to highlight difficulties and frustration with the referral process of young people to the inpatient unit. Whilst concern specific to an individual group is warranted, collaboration with other stakeholders and incorporating their specific concerns may provide solutions or at least, specific direction with the potential to benefit and meet the needs for all.

Declaration of Interest

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.
CHAPTER 4
I DON'T WANT TO BE HERE BUT I FEEL SAFE: REFERRAL AND ADMISSION TO A CHILD AND ADOLESCENT PSYCHIATRIC INPATIENT UNIT: THE YOUNG PERSON'S PERSPECTIVE


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Certification:

This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.

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Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate’s stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate to include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate’s stated contribution.

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Abstract

Early and appropriate intervention can assist children and young people manage their mental illness and prevent it becoming a long-term condition. However, satisfaction with mental health services can influence the level of engagement individuals are willing to participate in, beyond the time of the initial contact or hospitalisation.

A qualitative design was used to identify and understand the experiences of the admission process for young people referred to the sole psychiatric inpatient unit in one Australian state for children up to the age of 18 years. Eleven young people participated in semi-structured interviews that were audiotaped, transcribed and coded. Interview data were examined through thematic analysis.

Satisfaction with the inpatient experience was influenced by whether or not young people experienced a sense of connection with staff or other patients on the ward. The ability of nursing staff in identifying and catering to the individual needs of young people in their care facilitated feelings of safety, security and acceptance and contributed to the young person’s desire to remain engaged in treatment post-discharge.

This research supports the shift toward perceiving patient satisfaction as a separate entity from service delivery and quality, with some participants able to voice dissatisfaction around lack of services, while reporting overall satisfaction with the inpatient experience.

KEY WORDS: Child and adolescent, inpatient, psychiatric, satisfaction
Introduction

In most western countries, individuals with a mental illness, including children and young people, have basic rights around decisions about where and what type of care they should receive. However, many young people with mental illness do not voluntarily engage in professional help-seeking behaviour (Yap, Reavley, & Norm, 2013). Family or friends, the family doctor, or the school counsellor are often the ‘treatment’ choices preferred by young people (Rickwood, Deane, & Willson, 2007; Sawyer et al., 2000). Shame, stigma, embarrassment, and rejection, or being judged poorly by those from who help is sought, are possible reasons for this (Yap, Reavley, & Jorm, 2013).

There are occasions when admission of young people to a psychiatric inpatient facility is warranted, and ideally access to such services would be achieved on a voluntary basis. However, particularly in the case of need for treatment and the potential for danger towards self and/or others (Kaltiala-Heino, 2010), treatment can be enforced.

When either voluntary or compulsory intervention results in a negative experience, an individual might resist treatment again as required at a later stage. Intervention, although considered necessary at the time, might have resulted in a less than satisfactory outcome. A positive experience could result in willingness to continue treatment beyond the time of the initial contact or hospitalisation (Boyer et al., 2009; Bunge, Maglio, Musich, & Savage, 2014; Clarke & Winsor, 2010). Therefore, determining patient satisfaction is an essential step towards providing effective and appropriate care.

With greater understanding of mental illness and treatment, and with the drive toward consumer participation at all levels, the input of young people on
issues, such as consumer satisfaction, is now sought. The United Nations Convention on the Rights of the Child (1989) gives support to the idea that young people have the right to be involved in treatment decisions that affect them. This includes treatment regarding their mental health. Understanding patients’ perspectives and experience of care, and acting on those findings through models of care, might help to address issues of engagement and continuation of treatment for young people with mental illness (Boyer et al., 2009; Bunge et al., 2014; Clarke & Winsor 2010).

According to Gill and White (2009), while identifying levels of patient satisfaction is a highly desirable health outcome, it remains a poorly defined concept with no one universally accepted definition. It is also difficult to measure, possibly due to the multifaceted nature of satisfaction. Consequently, questionnaire-based research has often been employed, largely because it is a quick, easy and less expensive method of gathering data. Questionnaire-based research is not without its problems. Questions are often service-generated, focusing on aspects of care delivery that might not have the same degree of importance to the consumer. Similarly, and possibly the greatest criticism, is the inability of questionnaire-based research to describe the actual experiences of the individual regarding their care and how that in turn influences satisfaction (Webster, Gallaher, Lopez, Brown, & Evans, 2012).

Within public mental health services for children and adolescents, consumer satisfaction has not been studied extensively (Biering, 2010). Studies specific to child and adolescent perceptions of inpatient care are even more limited (Biering, 2010). From these studies however, three universal components relevant to adolescent satisfaction with mental health services have
been identified. They include: (i) Satisfaction with the environment and organization of the services (Grossoehme & Gerbetz, 2004); (ii) satisfaction with the adolescent-caregiver interaction, especially regarding the continuity of care; that is, having the same staff member involved for the duration of the treatment (Marriage et al., 2001); and (iii) satisfaction with treatment outcomes experienced as positive changes in thought, feelings, and skill acquisition (Gianello, 2002; Lee et al., 2006).

Areas of concern regarding standardization, low reliability and questionable validity of the instruments used (Biering, 2010; Hawthorne, 2006) make the generalization of results from questionnaire-based research difficult. In qualitative studies, of which there are few, asking participants what they perceive as a necessary change to ensure continuity in care, has rarely occurred. Clarifying the aspects of the inpatient admission that the young person identifies as satisfactory is an important area to explore. The advantage of applying a qualitative research approach is that it provides young people with the opportunity to describe all aspects of their admission experience, including referral and discharge. Open-ended interviews also allow for young people to make suggestions about changes or improvements in care relevant to the setting in which they receive that care, therefore, going beyond that which can be achieved by standard questionnaires.

This type of research adds valuable information to the literature that looks to explore aspects of care that are beneficial to the young person and contributes to their continuing in treatment post-discharge. The information derived could be unique to the site in which it is being undertaken. It is however, a process that can be applied across all child and adolescent mental health treatment settings,
eliciting information that can influence policy, procedures, and models of care. The aim of the present study was to identify and understand the experiences of the admission process for young people referred to an inpatient unit in one Australian state for children up to the age of 18 years who have a psychiatric illness.

**Methodology**

Approval was sought and received from the appropriate human research ethics committee.

**Recruitment**

A purposeful sampling technique was used for participant recruitment. Participants were children and adolescents admitted to an Australian inpatient unit in which the study was conducted. The unit was the only one of its type in the state. On admission to the ward, young people and their carers were informed of the study, and subsequent to initial consent to participate, were approached again at the end of their admission stay by the clinical psychologist (first author), where intent to participate was confirmed. The chief psychiatrist on the inpatient unit provided input regarding suitability (mental state evaluation) for participation. Potential participants were included in the study only if the interviewer had no current working (i.e., therapeutic) relationship with the young person referred to the inpatient unit.

**Consent.**

An information sheet outlining the aims and purpose of the study was prepared for recruitment of participants. Young people under the age of 16 years and their carers were asked to give their written consent for participation in the study. Young people 16 years and older were able to provide consent without
accompanying signed consent from their carer. However, all carers of participants 16 years or older included in this study, were aware of their child’s participation. Written consent was obtained prior to the interview being conducted, on the scheduled day of discharge.

**Participants.**

Eleven young people participated in the study, six males and five females. The age of the participants ranged from 15 years to 17 years. The diagnoses on discharge of the participants included depression, adjustment disorder, suicidal ideation/self-harm and situational crisis, with length of stay ranging from 4 days to 15 days. Four of the participants were admitted under an involuntary treatment order (ITO).

**Interviews.**

Interviews were conducted between March and November 2014. Open-ended semi-structured interviews, ranging from 15 min and 28 s to 50 min and 10 s, were conducted and audio-taped with participant consent, and were transcribed by the interviewer. All interviewees were aware of the interviewer’s position on the inpatient unit as a clinical psychologist, and reassurance regarding anonymity was repeated at time of consent and at the beginning of the interview. The interviewer was not involved in the clinical care of any participant.

Each interview commenced with the broad question: ‘Can you tell me about your experiences in being admitted to the inpatient unit?’ Additional interview questions were guided by the interviewee’s responses and were also complemented by previous participants’ responses. An audit trail was kept during data collection and data analysis. The audit trail guided the decision to
end sampling when data saturation was reached. Saturation refers to the point at which collected data are repetitive and are not conducive to new information (Morse, 1995).

**Data analysis.**

Interview data were analysed thematically following the guidelines of Braun and Clarke (2006; 2013). This method of analysis involves the identification of themes within and between participants’ transcribed interview data. The six stages of thematic analysis applied in the present study were: (i) data familiarization; (ii) code generation; (iii) theme search; (iv) theme review; (v) theme definition and naming; and (vi) report preparation (Braun & Clarke, 2006; 2013). All authors read the transcribed interviews, with the first author generating initial codes for the first interview, which were refined and recoded with input from all authors. The first author coded subsequent interviews. Emerging themes were then defined and redefined among all authors until the main themes were established. Checking of the themes by both the second and third authors enhanced methodological rigor and trustworthiness (Tracy, 2010). Participant validation of the transcripts was attempted, with no respondents requesting a viewing of their transcripts.

**Results**

The themes and subthemes extracted from the interview transcripts are summarized in Table 1.

Three overarching themes regarding each young person’s experiences with the inpatient admission emerged: Emotional response to the inpatient experience, Experiences of the admission itself, and Outcomes.
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<th>Overarching themes</th>
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<td>Discharge planning</td>
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**Emotional Response to Inpatient Experience**

Participants described positive or negative feelings, depending on whether they had initially agreed to the inpatient admission. Participants admitted under an ITO were most likely to report negative feelings, but did not exclusively. Participants’ initial responses to being admitted to the psychiatric inpatient unit were categorized under three subthemes: Acceptance, Powerlessness, and Fear of the unknown.

**Acceptance.**

Participants’ responses under this theme indicated a desire for intervention. “*I dunno if I was hoping it would happen, I just, well I just wanted to feel better and I needed help, so yeah, I guess it was alright*” (P11, 17 year old male).

**Powerlessness.**

Some participants expressed the perception that admission was beyond
their control and a consequence of decisions made by others. “I was in my bed. I didn’t want to, I didn’t want them there, but they picked me up and carried me to the ambulance” (P1, 15 year old female).

**Fear of the unknown.**

Participants’ expectations around what admission to the inpatient unit would entail were not always clear and contributed to feelings of uncertainty, including with regards to acceptance by other patients. “I didn’t know what to expect. I didn’t know if people were going to like me being there and like me as a person” (P2, 15 year old female).

**Experience of the Admission Itself**

This theme was representative of the perceived quality of care offered to the young person during the admission. Participants often compared the care they received in the inpatient unit, with the quality of care received in the community. Participants’ perception of their inpatient experience was represented by three subthemes: Interaction with others (staff and other patients), Environment, and Therapy.

**Interactions with others: Staff.**

Participants expressed high expectations of the inpatient staff in both levels of expertise, as well as degree of involvement in care. Participants, who were reluctant for admission, voiced an expectation of greater levels of interaction with nursing staff in particular that was not fulfilled. “The nurses are always busy. It’s like it’s a bother to ask them for anything. You always have to wait and sometimes they forget about you” (P11, 17 year old male). However, participants who were more accepting of the inpatient admission described a connection toward staff that they perceived lacking with others outside of the
hospital environment. “Outside of the ward, like if I’m back at school and I’ve tried to tell my teachers how I’m feeling, they don’t understand, they don’t really listen, but they do here, they get it” (P3, 15 year old female).

These participants also reported a perception that the inpatient staff were more capable than their community-based mental health clinicians, to deal with the serious or complex case presentations. “I don’t think she got it, and I really didn’t, you know, connect with her. Besides I don’t know if she can handle it. It would freak her out and she’d probably have just sent me here anyway” (P6, 16 year old male).

**Interaction with others: Patients.**

How young people related to their peers influenced the young person’s perception of the appropriateness of their stay on the unit. This in turn contributed to the overall level of satisfaction with the inpatient experience. Young people who did not seek out admission, described feeling frightened of other patients they considered more unwell than themselves, leading to a sense of not belonging. “I don’t see things that aren’t there. I make sense, she doesn’t. I don’t want to be here. I just don’t like getting out of bed so what?” (P1, 15 year old female).

When young people experienced some form of connection with peers, however, it was this relationship that they perceived responsible for making the inpatient experience a positive one “It’s the other kids that make it work; that gives you hope” (P10, 17 year old male).

**Environment.**

The subtheme ‘environment,’ included the participants’ perceptions of the physical environment and how it impacted on their mental health. Participant
responses highlighted how discontent or frustration around certain aspects of the inpatient unit could be acknowledged, without it affecting their overall perception of satisfaction with the inpatient experience. The physical environment of the inpatient unit was described by participants in negative terms around the lack of accessibility to an outdoor area within hospital grounds. “*We don’t have a balcony or outside area though*” (P7, 17 year old male).

Confinement was one aspect of the environment that participants highlighted, in discussing the restrictions that occur within a locked environment. “*The whole time I was here for a while I was thinking that, I don’t know what the word is, confined maybe in a sense, because you know sometimes they lock the doors because some people are here against their will, and I felt confined*” (P10, 17 year old male). However, participants also acknowledged some benefit to them from these restrictions. They described the physical aspect of the ward as a place of safety where the possibility of enacting on suicidal thoughts, was reduced to a remote possibility. “*Of course being here keeps me safe, for a suicidal person, it keeps me safe*” (P10, 17 year old male).

**Therapy.**

This sub theme included participant perceptions about the therapies that were provided to them during their admission. “Therapy” highlighted how individual needs of participants, as well as the degree of acceptance about being on the inpatient unit, influenced their perception of the usefulness of the type of therapy or intervention offered. Additional themes included ‘individual therapy’, ‘group therapy’, and ‘family meetings’.

**Individual therapy.** Participants who perceived the inpatient unit as a superior source of understanding and staff skill over that available within the
community, also perceived the inpatient unit to be the best place to commence or continue individual therapy. “They get me here, so here is where I should get help so that I can cope outside. I know it’s not the real world, but it’s not as scary, so I think I would feel better, accept more help if it came from here where I truly think people understand” (P10, 17 year old male). However, participants who were reluctant for admission were also reluctant to accept any intervention. “I ....,don’t need other therapy ’cause I have my psychiatrists” (P3, 15 year old female).

Group therapy. Participants reported a lack of clinician-led, therapy based group sessions. However, this perceived gap in service delivery was not viewed unfavourably. “When you are feeling really bad, it’s good not to talk sometimes. I’ve done group work before and it never works ‘cause that’s when I don’t want to talk, then none of the other kids want to talk either, so nah, maybe when I start to feel better, but even then, I prefer one-on-one” (P4, 16 year old male).

Family meetings. Favourable remarks by participants were made about the usefulness of family meetings, which the participants reported as difficult to replicate within the community. “My parents are divorced and they hate each other. They don’t even want to be in the same room together, so here on the ward they have to, they have to listen and talk” (P8, 16 year old female).

Outcomes

This theme included participant perceptions around personal and system-based changes. On a personal level, participants described how the inpatient unit impacted on their mental state and recovery. On a systems level, participants reflected on aspects of the inpatient experience they perceived as requiring
change or modification. The theme ‘outcomes’ included the following subthemes: ‘containment’, ‘advocacy and awareness’, ‘mental state,’ and ‘desired changes’.

**Containment.**

Participants expressed a perception of the inpatient unit as a place where they could not easily engage in self-harm and suicidal behaviour. “At home...It exhausts me. I have to keep me and other people safe. Here I don’t have to worry about myself” (P6, 16 year old male).

**Advocacy and awareness.**

Participants perceived the inpatient unit as a venue for them to speak through staff advocates to alert others of the difficulties and intensity of their distress. “It’s good that the staff here at least understand and can help my parents understand as well” (P9, 17 year old male).

**Mental state.**

Participants reporting a perception of improvement made reference to changed feelings or thoughts that were present at admission. “My calming down. I’m more calm, not going off at people, and talking to my psych who comes in to see me on the ward has been good” (P3, 15 year old female).

Participants were less likely to report the inpatient experience as beneficial, if there was a perception of little change or if expectations on admission had not been met. “They don’t talk to you they just pretty much leave you alone or send you down to school, and there’s nothing to do except talk to the other kids. So how am I supposed to get better? They don’t let you stay long enough. I didn’t get any medication, so what’s the point? (P11, 17 year old male).
**Desired changes.**

This sub theme included aspects of the inpatient admission that were identified by participants as unsatisfactory and requiring modification or change. Additional themes included: ‘information’, ‘ward activities’; and ‘discharge planning’.

**Information.** Participants reported a lack of available information explaining the nature of the inpatient admission prior to entering the unit. Lack of information was particularly problematic for participants who were admitted to the ward after normal working hours, with minimal staff and other patients already asleep, eliciting feelings of fear, uncertainty and discomfort. “I mean, I didn’t even know where I was, and then I was expected to just go to sleep and speak to someone in the morning. I thought someone would have explained more then. I didn’t even know who it was in the other bed; it was weird” (P11, 17 year old male).

**Ward activities.** Although the absence of therapist-led group sessions was not criticized, the lack of or minimal ward-based activities, such as art and craft, cooking, and outdoor-based activities, resulted in a negative perception of the inpatient experience. “It’s really boring. If I was here on my own it would be a hell hole. There’s not much to do” (P4, 16 year old male).

**Discharge planning.** Participants alluded to cooperative decision-making as influencing their perception of the inpatient experience, particularly with regards to discharge. Participants who were, from onset of admission, more open to inpatient care were also more likely than those who were not to seek out extended stay. “I need to stay longer, so I won’t hurt anyone and I’ll learn how to trust myself and ignore these feelings” (P6, 16 year old male).
In the absence of a longer length of stay, participants identified graduated discharge from the unit as a satisfactory alternative. “*Maybe during that time I would try having some leave, see if its ok, then have more leave, go see some friends, do what I do normally, maybe stay overnight and then go after that*” (P4, 16 year old male).

**Discussion**

The present study contributes to the body of research that supports the shift toward perceiving patient satisfaction as a separate entity from service delivery and quality. The qualitative nature of this research has enabled young people to describe their individual experience of admission and explain aspects of it that contributed to satisfaction and the desire to continue in care.

Participants who were less willing for the admission experience described strong negative emotions, such as fear, anger, and concern about how they themselves would be viewed by staff and other patients. They also expressed concern about whether they would be judged or accepted. These participants described a perception of existing inpatients’ problems as far more serious than their own, contributing to the perception of admission as being unwarranted. A lack of connection to any aspect of the inpatient experience was further exemplified by participants’ negative descriptions of care offered within the inpatient unit. Conversely, participants who were less oppositional to the idea of admission, perceived the inpatient admission as an opportunity to regain mental health in a place where assistance, support and understanding were experienced and contributed towards recovery.

In line with previous research, (Marriage et al., 2001) participants in the present study identified the adolescent-caregiver interaction as aspects of care
contributing to patient satisfaction. Participants accepting of admission viewed the inpatient referral as a means of access to highly skilled and experienced clinicians on whom they could unburden the responsibility of keeping themselves safe. This was something they perceived that could not be achieved in the community. The 24-hour care, rather than care specifically with one staff member for the duration of the stay, as previous research suggested (Marriage et al., 2001), was considered a positive experience. Young people admitted to the ward required different types and levels of intervention. The ability of the nursing staff to differentiate and advocate for the type of intervention the young person required and desired, influenced the overall perception of the inpatient stay.

Patient satisfaction was found in previous research to be linked to the environment of the hospital unit (Grossoehme & Gerbetz, 2004). In this particular study, participants were able to differentiate between unsatisfactory aspects of the ward, such as lack of open space and access to an outside area, from the benefits of being in a locked ward where means and access to modes of self-harm would be difficult. For this group of participants, a lack of services or amenities alone was not sufficient to determine patient satisfaction. Instead, aspects of care young people prioritized as important were an influencing factor.

For the participants, family meetings with an emphasis on advocacy and support were preferred instead of traditional therapies. Furthermore, fun based activities were the preferred form of group activity sought by both categories of participants in this study. Nursing staff that was able to provide these types of activities for the young people in their care, were instrumental in influencing the young person's overall perception of their inpatient stay.
Previous research has cited rejection or being judged poorly by those from who help was sought, as reasons why young people may not seek out help (Yap et al., 2013). To a degree these reasons appeared to apply to participants in the present study who did not believe that hospitalisation was merited in their case. However, participants who were more open to the idea of admission, reported perceptions of acceptance and non-judgment with other young inpatients on the unit with whom they had achieved some connection. This perceived connection was one of the most satisfying aspects of the inpatient admission and the driving force towards seeking extended stay and continued connection with both peers and treatment.

Previous studies have linked satisfaction with treatment outcomes, particularly with reported changes in cognitions and the perception of skill development (Geanellos, 2002; Lee et al., 2006). Participants in the present study acknowledged positive or no change in feelings, thoughts or behaviours, depending on their category regarding perceptions around admission. However, a lack of change or partial improvement did not necessarily result in dissatisfaction with the inpatient experience, if other needs already referred to had been met.

How discharge was determined and executed appeared to influence perceived usefulness of the inpatient experience, with planned and graduated discharge that maintains a connection to the unit, most favourably perceived. Young people who perceived benefit from the admission and were satisfied with the discharge process, were also most likely to desire continuity.
Implications and Recommendations

A strong sense of connection to other patients and with staff, and a belief that individual needs with regards to therapy and other interventions could be recognized and met, were aspects of care participants in the present study identified as satisfying. Willingness and a desire to remain engaged in treatment were perceived as more likely to occur as a consequence. These findings have implications for models of care.

As mental illness varies in type and complexity, a stand-alone and singular dedicated inpatient unit for children and adolescents might not have the capacity to meet the needs of everyone requiring inpatient care. A ‘step up and step down’ complex, where young people can move through depending on the nature and seriousness of their mental illness could reduce the degree of distress initially experienced by unwilling young people when admitted to the inpatient unit. This would also address the issue of graduated discharge requested by young people who have accepted the inpatient admission but still believe they require a greater duration of care. Furthermore, day programs offered by inpatient units might assist community-based clinicians who identify the need for further, more intense treatment for the young people in their care. In the past, hospitalisation might have been the only option.

When admission is considered the most appropriate treatment option, modifications to the way in which it is approached could reduce the degree of distress some individuals report. Nursing staff who spend the majority of the time with the young person admitted to the inpatient unit, play a very large role in both preparing the young person for admission and identifying with them the individual needs that can be addressed during the inpatient stay. This includes
the form of intervention and therapies that are most likely to engage the young person. Alternate therapies, such as art and music, might address the young person’s desire for treatment in an environment that offers opportunities to connect with others through ‘fun-based’ activities. Employing staff trained in these therapies or providing training opportunities for existing staff can enhance the overall ‘package of care’ provided to young people. When attempting to include young people in their own care delivery, with the hope of encouraging their adherence to treatment post discharge, these considerations are crucial.

**Strengths and Limitations**

The findings of the present study expand on previous research on patient satisfaction in child and adolescent mental health units. A strength of the present study is the reporting of opposing perceptions of care based largely on the young person’s willingness or reluctance for admission to the inpatient unit, which has not been identified in previous research. A further strength has been the ability to derive from participants,’ an insight into changes that could improve the likelihood of continued engagement with young people in mental health treatment.

The present study has some limitations. The single site from which participants were recruited potentially limits the generalizability of the findings. Furthermore, the findings are based on the perspectives of a select group of individuals, aged 15-17 years of age, and who were not admitted with a diagnosis of psychosis. The inclusion of younger individuals, as well as those who had been admitted with severe mental illness, might have provided a different perspective.
CHAPTER 5

IN THIS DAY AND AGE WHY IS IT STILL SO HARD TO FIND THE RIGHT TYPE OF HELP? CARERS' PERSPECTIVES AROUND CHILD AND ADOLESCENT MENTAL HEALTH SERVICES: A QUALITATIVE STUDY.

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<th>In this day and age why is it still so hard to find the right type of help? Carers’ perspectives around child and adolescent mental health services: A qualitative study.</th>
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Certification: This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.

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**Co-Author Contributions**

By signing the Statement of Authorship, each author certifies that:

i. the candidate’s stated contribution to the publication is accurate (as detailed above);

ii. permission is granted for the candidate in include the publication in the thesis; and

iii. the sum of all co-author contributions is equal to 100% less the candidate’s stated contribution.

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Abstract

The aim of this study was to identify perceptions and experiences of children and young people accessing mental health services in one state in Australia from the perspective of their carer.

Semi-structured interviews were employed in this qualitative study with eleven carers of children admitted to a child and adolescent psychiatric inpatient unit. Interviews were audiotaped, transcribed and coded. Thematic analysis following the guidelines of Braun and Clarke (2013) was applied to the interview data. This method of analysis includes: data familiarisation, code generation, theme search, theme review, theme definition and naming and, report preparation. Three overarching themes emerged; experiences prior to admission, expectations around admission, and the in-patient experience.

Contrary to previous research, satisfaction with mental health services was found to be greater in in-patient units. Dissatisfaction with community-based mental health services focussed on poor accessibility, long waiting times, exclusion from therapy sessions and incomplete assessments that often warranted additional specialist intervention. Carers living in country, rural and remote regions of the state were most vocal in dissatisfaction with community-based services.

Carer perceptions of the inpatient unit as the most desirable and appropriate form of mental health intervention for their child, goes against the current shift in treatment focus to provide care in the least restrictive environment, that is the community. This has implications for future service delivery and design and supports research that has highlighted carer satisfaction to being closely linked to factors other than clinical improvement.

KEY WORDS: carers, child and adolescent, inpatient psychiatric unit, satisfaction
Introduction

Over the last few decades, advances in mental health have meant that treatment for people suffering from mental illness including children and adolescents, is favoured to occur in the least restrictive environment, that is, the community, with inpatient admissions restricted to brief treatment focussing on crisis stabilization, assessment and discharge planning (Hopkins, Loeb, & Fick, 2009; Moses, 2011). This has meant that for carers of young people suffering from mental illness, the burden of care for their child lies heavily on their shoulders and with community-based mental health services.

Research around child and adolescent mental health services from the perspectives and experiences of carers of young people with mental illness is limited (Gill, Butler, & Pistrang, 2016). That which does exist suggests that the impact on carers and the family in coping with the range of mental health related problems faced by their children can be quite devastating, often exacerbating existing problems and tension. Carers report feelings of loss and grief around the mental illness diagnosis, as well as physical and emotional exhaustion in living with and managing the condition (Delaney & Engels-Scianna, 1996; Gopalan et al., 2010; Mohr & Regan-Kubinski, 2001). Seeking help for the young person can further exacerbate these feelings and concerns with carers often unsure and fearful of how their child will be treated and cared for. The appropriateness of the treatment as well as the stigma associated around treatment itself is also a source of concern (Askey, Holmshaw, Gamble, & Gray, 2009; Mukolo, Heftinger, & Wallston, 2010).

How satisfied a carer is with the mental health services offered to their child is likely influenced by how well their own concerns have been addressed.
How well their concerns have been addressed is also likely to influence how actively the carer encourages and supports their child’s connection and continuity with mental health services (Azzi-Lessing, 2013; Rey, Plapp, & Simpson, 1999; Scharer, 2000). It is imperative therefore, that in service delivery, the involvement of carers occurs.

Previous research has identified the type of involvement carers find satisfactory when seeking assistance for their child. An effective therapeutic alliance between parents and mental health providers, practical and emotional support, education about the illness and treatment, and affirmation of the carer’s role and impact on the child, have all been linked to carer satisfaction (Brinkmeyer, Eyberg, Nguyen, & Adams, 2004; Crow et al., 2002; Gavidia-Payne, Littlefield, Hallgren, Jenkins, & Coventry, 2003; Gerson et al., 2009; Jakobsen & Severinson, 2006; Pinfold et al., 2005; Scharer, 2002; Tarico, Benson, Trupin, & Forsyth-Stephens, 1989). Feeling disrespected or judged poorly by the mental health service provider, lack of recognition around the level of expertise in their child’s problems and needs, and perceived hostility toward parents’/carers’ desire to be involved in the treatment of their child, can all contribute to carer dissatisfaction. Dissatisfaction has also been found to be greatest across inpatient settings (Ewerton, Lutzen, Svensson, & Andershed, 2010; Geraghty, McCann, King, & Eichmann, 2011).

In Australia, surveys have become popular means of capturing consumer experiences in service delivery. They have become the tool often utilized in determining advances that have been made and changes that may be required. Surveys however, are often service driven and often do not allow the respondent to describe the actual experiences around care and how that in turn influences
satisfaction (Webster, Gallaher, Lopez, Brown, & Evans, 2012). In order to overcome shortcomings inherent in survey style measures, Lelliott et al. (2001) suggested that it was important to listen to what the consumer wants or needs because service providers cannot assume to know what service outcomes are of importance to service users. Qualitative studies are in this instance preferable, as they are able to provide in depth information about the lived experience of consumers that can be used to both evaluate the service, identifying its strengths and weaknesses from different perspectives, as well as influence future service type and delivery (Alvarez et al., 2012; Jones et al., 2009). It is a process therefore, that can be easily replicated across treatment settings and across different consumer groups.

This study examines the expectations, perceptions and experiences of carers around accessing mental health services for their child, including inpatient admission. A qualitative approach applying an interview format guided by open-ended questions was selected for this study. This approach enhances the depth and breadth of information beyond that which fixed format standardized questionnaires are likely to achieve (Alvarez et al., 2012). It also reduces researcher bias and allows for greater focus on what the consumer views as relevant and necessary for change (Shenton, 2004).

Child and adolescent mental health services in this study, refers to the community-based services available within the state (both country and metropolitan) in which this study was conducted. It includes the sole inpatient psychiatric unit for children and young people up to the age of 18 years.

The inpatient unit in this study provides comprehensive and specialised care and support for children and adolescents with severe mental health problems
including psychosis, depression, suicidal ideation and intent, and complex and coexisting disorders. The number of admission episodes in the year in which this study was undertaken, exceeded 500, with an average length of stay of 5 days. Individuals with severe disorders such as psychosis and major depression, experience a length of stay beyond the average, whilst those admitted in crisis more likely to experience a length of stay below the average. The philosophy of care for all public inpatient and community-based services is to provide care in the least restrictive environment. The inpatient unit facilitates transition back to the community where it is anticipated that the long-term therapy if required, will occur.

**Method**

Semi-structured interviews following the guidelines of Braun and Clarke (2013) were used in this qualitative study. Approval was sought and received from the appropriate hospital-based Human Research Ethics Committee (Approval number: 2511/10/2015).

**Recruitment**

Participants were recruited from the list of carers accompanying young people admitted to one inpatient unit. At the time of admission, the admitting nurse informed both the young person and the carer about the study. Only carers of young people with whom the first author and interviewer, who was the clinical psychologist on the inpatient unit, had no professional or working relationship with, were approached for participation. Additional information was offered around the nature of the study and those who had confirmed interest in participating, were offered an appointment time to conduct the interview. Non-English speaking carers were excluded from the study, as were carers of children
with a length of stay of 24 hours or less, due to time constraints around arranging
and conducting interviews. All carers approached meeting the inclusion criteria,
agreed to participate in the study.

**Consent and confidentiality.**

Potential participants were provided with standardized information sheets
prior to being asked to give their written consent for participation in the study.
Written consent was obtained on the day of the interview (day of discharge).
Confidentiality, privacy and anonymity were assured for all participants. Audio
taped interviews were transcribed with only de-identifying information provided.
Once transcribed and following final analysis, the audiotaped interviews were
erased.

**Participants.**

There were 11 participants: 9 women and 2 men. Ten participants were
biological parents of a young person admitted to the inpatient unit. One of the 11
participants was the maternal grandmother and legal custodian of the young
person in her care. The diagnoses of children of carers admitted during the time
of the investigation included adjustment disorder, suicidal ideation/self- harm,
depression, psychosis (schizophrenia), mania, and delusional disorder. Length of
stay ranged from 2-35 days. Two of the children were admitted under an
Involuntary Treatment Order (ITO).

**Interviews.**

Interviews were conducted between December 2014 and June 2015 in an
office off the ward at the hospital in which the carer’s child had been
hospitalised. Open-ended semi-structured interviews ranging from 28 minutes to
55 minutes were conducted and audio taped with participant consent, before transcription by the interviewer.

Each interview commenced with the broad question: “Can you tell me about your experiences around accessing mental health services for your child?” Additional interview questions were guided by the interviewee’s responses and were also complemented by previous participants’ responses. An audit trail was maintained during data collection and data analysis. The audit trail guides the decision to end sampling when data saturation is reached, that is the point at which collected data become repetitive and are not providing new information (Morse, 1995).

Data analysis

Thematic analysis following the guidelines of Braun and Clarke (2006; 2013) was applied to the interview data. This method involves six stages of analysis including: 1) data familiarization, 2) code generation, 3) theme search, 4) theme review, 5) theme definition and naming, and 6) report preparation. Emerging themes were initially identified and defined by the first author and subsequently redefined by all authors, until the main themes were established. The checking of the themes by both the second and third authors enhanced methodological rigor and trustworthiness (Tracy, 2010). Participant validation of the transcripts was attempted, with one respondent making grammatical change to the text in order to improve readability. The other respondents made no changes.

Results

The research question that guided this study was: Are mental health services provided by community mental health services in the state in Australia
in which this study was undertaken, meeting the needs of carers of young people? Three overarching themes emerged: Experiences prior to admission; Expectations around admission, and The inpatient experience.

**Experiences Prior to Admission**

Participants described scenarios where they felt frustrated, annoyed and disappointed with the perceived inconsistency in availability and perceived quality of care offered by non-hospital based services in particular. Many also expressed a belief that the inconsistency in care was potentially detrimental to the overall mental health of their child. The subthemes representing these perceptions include: Accessibility, Service quality and Barriers to admission.

**Accessibility.**

There was a perception that community-based services for young people were difficult to locate and to access. "I think there should be more supports in the public that should be listed so you can find it easily, it should be up there for everybody to see and readily available to people, not being so hard to find" (grandmother of child with suicidal ideation). This lack of accessibility was particularly problematic for carers of young people living in rural and remote locations. A sense of helplessness around coping with their child in the absence of mental health support was often expressed. "You go and see the mental health people at (nearest big country town). Then you got to wait at least another three or four days for someone else, a mental health specialist, to come down and see them, so you go to travel again, and in the meantime, what are you supposed to do about managing?" (mother of daughter with depression).
Service quality.

Participants whose children had received community-based mental health services, reported mixed experiences around perceived quality of care. The concerns included; frequency of appointments, insufficiency of treatment, and exclusion from therapy sessions.

*Frequency of appointments.* The frequency of appointments was perceived by participants as inadequate for in-depth assessment and diagnosis. "*In the community they only see her maybe tops twice a week and so it’s a bit hard. We explain what she’s like but it’s a bit harder if you don’t see it. You know it was hard before she came to hospital because no-one could work it out*."

Furthermore, the infrequency of appointments was perceived as providing limited support to carers who were solely responsible for the wellbeing and management of their child from one appointment to the next. "*So for 8 months nearly, we had a hard time at home*" (mother of daughter with mania).

*Exclusion from therapy sessions.* Participants, although acknowledging the need for their child to speak privately with therapists, expressed a desire to be included in therapy sessions, and dissatisfaction when this did not occur. "*I felt very angry and hurt until we saw (therapist) and she said, no you can come in on the meetings*" (mother of son with suicidal ideation/self-harm). The exclusion from therapy sessions by carers was perceived as lack of recognition of the role they play in managing and maintaining the mental health of their child.

The perceived insufficiency and inconsistency of care offered and the desire for "more" for their child, contributed to carer perceptions that their child’s needs might best be met through inpatient care. However, participants also reported experiences around difficulties in achieving admission.
**Barriers to admission.**

This sub-theme concerns carer perceptions around accessibility to inpatient mental health facilities. When the carer or referring parties believed that hospitalisation was the required treatment choice, frustration was expressed when further assessment did not result in hospitalisation. "*They said that she desperately needs help, she sees a figure following her around all the time telling her to do things, so he said that she needed help, but we went to the (general medicine) hospital first, then we were referred to the children's hospital and they questioned her and then sent her home*" (mother of daughter with depression). Participants reported that the difficulty in accessing services resulted in a further decline in their child’s mental health.

**Expectations around Admission**

**Assessment.**

Participants viewed the hospital admission as an opportunity to provide an in-depth assessment based on 24-hour care and observation. "*Well in the hospital the nurse can keep an eye on her for 24 hours. That makes a big difference I suppose. They can judge her personality and how it changes*" (mother (1) of daughter with mania). This was a process that participants perceived as not being able to be achieved through outpatient appointments. The second opinion by a mental health professional provided through such an assessment process was perceived as highly desirable in order to facilitate appropriate treatment, both during the admission, as well as post discharge. "*Somebody else would have seen her, that can back it up and that can tell the people that we've gone to see, like at [mental health service], what their opinion"
is, and what needs to be done, what help she needs to keep getting so that she doesn’t hurt herself” (grandmother of child with suicidal ideation).

**Inpatient Experiences**

Participants in this study overwhelmingly expressed the belief that the admission of their child to the inpatient unit was warranted and that it was a better alternative to community-based care. “I think we have a better understanding of what’s been happening for (son). It has gotten us more help, more regular help. I’m glad he’s here because I can see he can do it, he can go to school, he can go to the gym” (mother of son with suicidal ideation and self-harm). The desire for a thorough assessment, understanding of the existing problem, treatment and hope around possibility of recovery for their child, were perceived as having occurred as a consequence of the inpatient admission.

**Relationship with staff.**

Availability of multidisciplinary inpatient staff, who carers could communicate with throughout the day around concerns and decision-making, was viewed in positive and satisfactory terms. “They always tell me in the morning how his night has been when I ring up, they tell me what the plan is for the day and they always ask me if I have any questions. They call me in for meetings we’ve had about three already and they make sure it is at a time I can make, so that’s all good too. Everyone’s been good” (mother of son with psychosis).

**Ongoing concerns.**

Although acknowledging a greater sense of satisfaction and security around the care of their child during the inpatient admission, concerns resurfaced at point of discharge. Those most concerned often linked the perceived
inadequate duration of care as a factor. The sub-theme ‘ongoing concerns’ is supported by additional sub-themes ‘length of stay’, ‘relapse’, ‘safety,’ and ‘desired changes’.

Length of stay. Participants were universal in their disappointment with the length of stay experienced by their child. “Well a week’s not long enough to get better or actually help him stay better” (mother of son with suicidal ideation/self-harm). Participants were consistent in their reported fear of improvements gained during the inpatient admission, not being maintained post discharge.

Relapse. Participants, who were unhappy with the length of stay, were also more likely to express concerns around their child relapsing. “I’d be really upset if he goes backwards, I want him better, I’m hoping that he is going to be fine in the community”. Reassurance and guarantee from hospital staff that their child would progress post discharge, was also sought. “I want the hospital to tell me that he’s going to be fine and back to his normal self” (mother of son with suicidal ideation/self-harm).

Safety. Despite acknowledging the education and support provided by the inpatient unit, many participants identified their own sense of inadequacy around knowing how to keep their child safe once discharged. “They’ve explained everything to us, but no offense, we have heard it all before, we understand why she might be doing what she is doing but none of that takes the feelings away, none of that makes us feel safe” (mother of daughter with suicidal ideation).

Desired Changes. Participants discussed changes to the inpatient experience that they perceived as beneficial to both their child and themselves as
carers. Changes focussed on service type and delivery, as well as environmental factors.

In addition to the desire for a longer length of stay, participants expressed the desire for children to be accommodated according to their perceived degree of “wellness”. For example, young people requiring greater input from the inpatient unit in terms of assessment, treatment and support, accommodated in a ‘higher dependency section’. “Maybe a separate section for the really, really unwell kids who first come in”, whilst young people requiring less intense intervention, accommodated in a different section of the ward “and then another section for those that are getting better” (mother of son with psychosis).

*Continuity in care.* Participants acknowledged that having a known therapist with whom their child has established rapport, would be perceived as more beneficial in the long term for their child. “Actually since she’s already been here why can’t she see the same person as an outpatient that would be better than having to start all over again with someone who really doesn’t know her” (mother of daughter with adjustment disorder). Participants expressed a preference for their child to receive outpatient care from inpatient staff. In the absence of this possibility, participants expressed a desire for the mental health specialist providing care post discharge to their child, to attend meetings and be active in post discharge planning, whilst their child was still an inpatient.

“Maybe if the person she is supposed to see in the community team could have seen her here while she was on the ward so she could already know what’s happening before, then that would be better” (mother of daughter with adjustment disorder).
Discussion

This study attempted to explore the experiences of carers during the process of accessing mental health services for their child. Participants viewed the perceived lack of appropriate and accessible community-based mental health services as not meeting their or their child’s mental health needs. By identifying factors carers found lacking, and identifying aspects carers felt would assist them in the care and management of their child’s mental illness, implications around service design and delivery are made.

Contrary to previous research (Geraghty et al., 2011), participants in this study reported greater dissatisfaction with community-based settings rather than the inpatient unit. The difficulty in accessing community-based mental health services, the perceived infrequency of appointments and inconsistency in treatment offered, as well as at times poor rapport with treating therapists, was perceived by participants as contributing to a decline in the mental health of their child. People living in rural and remote areas of the state, were particularly dissatisfied with accessibility, having to travel additional kilometres in order to access services and having to wait even longer times than their metropolitan counterparts, for specialist mental health assistance. Participants voiced dissatisfaction, fear and distress in having to carry the burden of responsibility for the safety and wellbeing of their child whilst attempting to seek out appropriate care.

Factors identified in previous research as important to carers of young people suffering from mental illness, such as a comprehensive assessment of their child, inclusion in decision making around their child’s care, positive interactions with staff, education about their child’s illness, and liaising with
other services on behalf of the child and their carer (Brinkmeyer et al., 2004; Crow et al., 2002; Gavidia-Payne et al., 2003; Gerson et al., 2009; Pinfold et al., 2005), were also perceived as satisfactory aspects of the inpatient care by participants of this study.

Disappointment with community-based services appeared to result in carers continuing to actively seek out hospitalisation for their child, in the hope that the inpatient unit could provide the support they perceived lacking in the community. This was the case even when attempts at having their child hospitalised failed previously. It also influenced the desire for carers to seek out longer lengths of stay for their child, fearing treatment in the community would not be sufficient to maintain any improvements made from the inpatient stay. Participants perceived in-patient care as not only the most appropriate for their child, but as providing them with a sense of relief at not having to assume complete and sole responsibility for the management of their child’s illness and safety.

This preference for hospital-based services is in contradiction to the desired evolution of care from hospital to community-based care. It is not necessarily unexpected. The preference for hospital-based care can be explained around the concept of containment. Containment is an aspect of inpatient care children and adolescents themselves have identified in previous studies (Gilburt, Rose, & Slade, 2008; Haynes, Eivors, & Crossley, 2011; Hepper, Weaver, & Rose, 2005) as a positive aspect of the inpatient experience. An inpatient unit provides both physical containment of the individual and emotional containment for the carer who is often experiencing fear around maintaining their child’s safety. The fact that the child has been hospitalised instils in the carer the
perception that the treatment offered is intensive, continuous and productive. Community-based care, as described by participants in this study, is often sessional and inconsistent and at times also perceived as exclusive of carer involvement.

Participants in this study viewed inclusion in the treatment of their child as highly important. Community-based teams that were perceived as not actively encouraging inclusion of carers in therapeutic sessions with their child resulted in anger and frustration on the part of the carer. However, advances in mental health has meant greater acknowledgement of the consumer in decisions around their care. This includes enabling young people to have a voice and be heard. Young people 16 years and over in the Australian state in which this study was undertaken, are able to give informed consent about their treatment options. This includes honouring the request to not involve their carers in the provision of services offered. In order to respect the wishes of young people (Ward-Griffen, Schofield, Vos, & Coatsworth-Puspoky, 2005) and maintain rapport which in turn might influence continuity in care (Rey et al. 1999; Scharer, 2000), choosing not to include carers, is not a decision that is taken lightly.

In the inpatient unit where the end result of the time limited care is often ‘discharge home to the carer’, emphasis on attempting to include carers in treatment and discharge plans is mandatory, unless specifically requested otherwise by the child. Even then, explanation around reasons for non-inclusion is offered to the carer, and compromise between child and carer is attempted. This is of particular importance with children who present with chronic self-harm and suicidal attempts. Carers are often in a heightened state of distress around maintaining safety for their child and must be included in management plans. If
inclusion in therapy with their child is not feasible, then providing additional support for carers, such as individual appointments for them on a more regular basis, is an alternative. Although this is a process that often does occur in community-based teams, participants in this study perceived the frequency to be insufficient.

As participants viewed the inpatient unit as “the right place” for their child, the prospect of discharge trigged fear and uncertainty, particularly for carers of children with suicidal and self-harm behaviours. Children and adolescents transitioning back to the community have in previous research, also identified the point of discharge as a time of concern (Gill et al., 2016). Although participants acknowledged greater understanding of their child’s illness as a consequence of the admission process, that did not alleviate any of their concerns around responsibility for ensuring their child did not relapse once discharged. This concern highlights the need for additional support for families that can act as a buffer between inpatient and outpatient care for young people deemed at high risk.

Mental health service delivery pathways in the state in which this study was conducted, are designed for post discharge follow-up to occur outside of and separate from the inpatient unit. However, carers in this study continued to favour contact with inpatient services and staff post discharge of their child. This is a novel result. The suggestions offered by carers included a separate step down unit that caters for long-term admissions and specifically for young people at risk. In this absence of this, carers suggested more active participation in the admission episode by the community-based mental health team who would be responsible for care of their child post-discharge. Although this is a process that
is already encouraged in the state in which the study occurred, in reality it has proven difficult to achieve. Community-based mental health clinicians often operate on a diary basis and availability to attend hospital-based sessions is not easily achievable without sufficient notice. The length of stay, which is often around 5 days, contributes to this problem. Creativity around service delivery is required and the use of Telehealth facilities, face-time, phone link-up or after hour consultations may warrant further investigation.

The results of this study support the existing literature that states carers’ desires for education around their child’s illness, inclusion in the management and decisions around care of their child and respect for their knowledge and expertise around their child’s mental health issues is of great relevance in influencing satisfaction with mental health services. This study has also highlighted that when these desires and expectations are not met, then dissatisfaction and reluctance to return to the service deemed “lacking”, in this case, community-based mental health services, is likely to occur.

This study has identified the specific reasons for why hospitalisation is desired as the most appropriate form of intervention for young people, when most previous research, identifies it as the source where most dissatisfaction occurs (Geraghty et al., 2011). Safety, risk and the anxiety around managing these aspects of their child’s mental illness was repeatedly identified by carers as a source of concern that can only, for those participants in this study at least, be contained by a secure inpatient unit. The intensity and frequency of assessment and review is another reason for the preference for inpatient, as opposed to, community-based care.
When concerns around service type, availability and accessibility are repeatedly raised, changes to accommodate concerns must be considered and where appropriate, made. Participants in this study have clearly articulated their concerns around maintaining their child’s safety and request additional community-based services or changes to service delivery that can “share the responsibility” and lift the burden of care. Providing care in the least restrictive environment can only be a successful evolution if appropriate supports are available to those individuals responsible for providing that care.

This study adds to the very limited body of research around the referral and admission process of young people suffering from mental illness from the perspective of their carer. Furthermore, it sets the path for research that aims to identify appropriate support and resources required to assist carers in managing the mental health of their children. This is particularly important on the background of policy that aims to provide care for young people experiencing mental health problems in the least restrictive environment.

A relative weakness of this study is that the findings may be relevant only to state in which this study was conducted, as comparisons with other mental health services elsewhere were not attempted. Furthermore only parents/carers with children admitted to the inpatient unit were included in this study, therefore potentially influencing their preference for hospital over community-based care. The exclusion criteria for participants in this study resulted in categories of participants for whom we have no information around the inpatient experiences of their child. Information is lacking on the perceptions and experiences of carers of young people who did not accompany their child to the inpatient unit at admission, or from carers whose child’s inpatient experience was of duration, 24
hours or less. The exclusion of non-English speaking carers has also resulted in a lack of perspective from culturally and linguistically diverse individuals. However, the process of evaluating a mental health service from the perspective of any consumer group is one that can be applied universally.

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CHAPTER 6

CONCLUSION

Summary of Findings

Understanding of consumer satisfaction with psychiatric inpatient care for children and adolescents was enhanced by the inclusion of a current systematic review of the literature. Separate analysis of all three relevant consumer groups: referring clinicians, young people admitted to a psychiatric inpatient unit, and parents/carers of young people admitted to an inpatient unit, included in this research project, provided specific information on satisfaction relevant to each consumer group. Triangulation of results provided a more robust and comprehensive understanding of consumer satisfaction identifying from multiple perspectives, aspects of care that were perceived as requiring change or modification.

Examination of the available literature (Paper One) identified very little published research on satisfaction with child and adolescent psychiatric inpatient care. The seven quantitative studies identified suffered methodological inconsistencies around surveys and questionnaires used to gather information that were not tested for validity and focussed on service specific aspects of care, making generalizability of results difficult. The seven qualitative studies identified in the review, although overall of better quality in design than the quantitative studies, were not without their limitations. Potential bias through recruitment of participants, interview methods used, pooling of results without differentiating on the basis of treatment site, interventions used or population characteristics, resulted in findings that appeared of relevance only to the site in which the studies were conducted.

170
In spite of the methodological flaws and inconsistencies in data collection and analysis across the studies in the review, satisfaction with mental health services for children and adolescents receiving inpatient care appeared linked to: positive interactions with other staff and patients; perceived changes in the reasons for admission or referral; interventions that included carers and referring clinicians; and good discharge and follow-up plans, with the absence of same, resulting in an unsatisfactory experience. These findings were consistent with an earlier systematic review undertaken by Biering (2010), as well as with the findings of the three studies undertaken for this thesis focussing on referring clinician, child and adolescent, as well as carer perceptions and experiences with referral and admission to a child and adolescent psychiatric inpatient facility in one state in Australia. The findings from the studies in this thesis (Papers Two, Three and Four) however, by focussing on a methodologically stringent qualitative approach, yielded results that were able to identify and clarify, not only aspects of care that were considered satisfying, but included suggestions around change and modifications to service design and delivery that might enhance adherence to treatment, and increase the likelihood of improvement and recovery.

Understanding what aspects of a service design and delivery are satisfactory is an important and worthwhile pursuit. The applicability and transferability of a research approach that yields significant and relevant information, is arguably as important as the transferability of the results obtained. The studies undertaken in this thesis elicited valuable information around service satisfaction, with the potential to influence major changes in service design and delivery.
An examination of the experiences of referring mental health clinicians to the only psychiatric inpatient unit for children and young people in the state in which the study was undertaken (Paper Two) included perspectives from the disciplines of psychiatry, psychology, medical, nursing, social work and occupational therapy.

A unique finding in this study was the referring clinicians’ actual experiences and concerns around managing young people in the community who are deemed to be at high risk and difficult to engage. These concerns were a driving force for referral and admission to the inpatient unit. Referring clinicians described scenarios where they felt the need to use language that focussed more on the biomedical with emphasis on risk, and less on the psychosocial aspects of the young person’s condition, even when that was perceived by the referring clinician as a valid ‘stand-alone’ indication for admission. The need to “sell” the referral to the inpatient unit was perceived as counterproductive and unhelpful, for either the community-based clinician, or the young person attempting to maintain their safety and well-being.

Participants in this study placed a heavy emphasis on clinical improvement having occurred in the young person before being discharged from the inpatient unit back to their care. The perceived lack of cognitive based therapies and short length of stay, with poorly defined discharge plans, and no perceived change in patient circumstance, contributed to referrer anxiety. Whilst these areas of dissatisfaction were similar to those found in previous studies (Chung et al., 1995; Marriage et al., 2001), the reliance on the inpatient unit for intervention beyond containment and assessment, is in contradiction to mental
health provision occurring in the least restrictive environment, that is, the community (Hopkins et al., 2009).

Young people admitted to the inpatient unit were interviewed about their experiences around referral and admission to the psychiatric inpatient unit (Paper Three). Two categories of participants were identified: those wanting admission and those who did not.

Young people non-accepting of the admission described the circumstances around referral and the time spent in the inpatient unit, in unfavourable terms. Young people admitted against their wishes, perceived a sense of disconnect from other young people in the inpatient unit, reported a poor or indifferent relationship with staff, and were rejecting and or critical of any intervention offered. The opposite was found to be the case for those young people who perceived the inpatient admission as either desired or required.

Participants in favour of admission also perceived the nature of their mental health problems as too difficult for community-based clinicians, perceiving inpatient staff to be more appropriately skilled and qualified than their community-based counterparts. This was a novel finding. These participants also perceived the inpatient unit as a means of offering ‘containment’ and a ‘sense of relief’ at no longer having to bear sole responsibility for keeping themselves safe. The perception of containment that an inpatient unit can provide has been identified as a source of satisfaction in more recent research (Gill et al., 2016).

Traditional cognitive based therapies were not popular among young people admitted to the inpatient unit. This is in contradiction to what referrers to the unit (as identified in Paper Two) believed young people required as part of
their inpatient experience. Instead, young people preferred alternative therapies, such as art and music therapy. Family meetings, with an emphasis on psycho-education and staff liaising on the part of the child however, were viewed favourably. Young people perceived the inpatient experience as providing an opportunity for their families to come together and understand the seriousness of their mental health problems. Young people admitted to the inpatient unit and favourable to the admission, perceived this as unlikely to occur in the community.

The connection young people had with both staff and other patients on the ward influenced their perceptions and attitudes around the inpatient admission in general, and around length of stay and discharge specifically. Young people who sought out admission were reluctant for discharge back to their community-based treating team, preferring instead, continuity in care with the inpatient unit. Concerns around transitioning back to the community have been raised in subsequent research (Gill et al., 2016). Concerns around relapse and not having experienced enough opportunity during the admission episode for real change to occur, contributed to desire for continuation in inpatient based care.

This study’s findings contributed to the limited body of research around child and adolescent perspectives of psychiatric inpatient admission identifying where previous research lacked, specific aspects of the admission that proved satisfactory, and aspects of service delivery post discharge, that might enhance continuity in care. The services identified reflect the young person’s desire for “normalcy,” which in this paper was identified to imply a sense of connectivity with others whom young people perceived as similar to themselves. The
perception of superiority of inpatient care over community-based care, further challenges mental health service delivery in the Australian state in which this study took place.

The perceptions of carers of young people admitted to the inpatient unit, was the focus of Paper Four. Carers who participated in this study included biological parents and grandparents. Carers were universal in their perception of the inpatient unit as being the most appropriate treatment centre for their child. This perception was influenced strongly by their shared experience at frustration around community-based mental health services. Difficulty in locating services, long duration between appointments, perceived inconsistency in quality and type of service offered, lack of inclusion of parents in treatment sessions and decision making around care and management of their child’s mental health, was perceived as contributing to deterioration in their child’s well-being. Similar concerns have been identified in previous research, although the dissatisfactions in those studies were aimed more at inpatient care (Brinkmeyer et al., 2004; Crow et al., 2002; Gavidia-Payne et al., 2003).

Carers perceived the inpatient unit as fulfilling most of their expectations and desires around care, and as being able to provide the necessary treatment to aid towards recovery. They also perceived the inpatient unit as providing the necessary containment for maintaining their child’s safety and security as well as their own anxieties and concerns for their child, by providing respite and support.

The perceived superiority of the inpatient unit over community-based care identified initially by children and adolescents in Paper Three was also a perception expressed by carers. That led to both categories of participants to attempt to negotiate for longer lengths of stay, graduated discharge, and for
continuity of care to be provided post discharge by inpatient staff. For carers in this study, post discharge community-based options remained unsatisfactory and lacking.

**Significance of Findings**

The findings of this thesis both reflect and further contribute to findings in previous research around consumer experiences with mental health services. Some of these experiences have been described previously anecdotally, in journal manuscripts and through individual accounts. However as shown in the systematic review of the literature, actual published research evidence is lacking.

People suffering from mental illness, as well as those individuals charged with caring for them on either a professional level or through family circumstance, know the difficulties encountered in being held responsible for keeping an individual safe and guiding them towards containment and hopefully recovery. Fear, distress and heightened anxiety are just a few of the emotions individuals coping with mental illness experience. This study has explored in detail the reasons for these concerns as well as identified possible means by which some of these concerns can be alleviated.

Safety and containment was a universally recognised theme across the three groups of participants with all overwhelmingly identifying the inpatient unit as the most appropriate environment for young people with suicidal ideation and self-harm behaviour. Length of stay for this diagnostic group of individuals was also universally perceived as inadequate. Participants from all three study groups identified the length of stay as too short to have resulted in meaningful change, either clinical or psychosocial. Referrers, young people and carers, all voiced a lack of confidence in resources available to them in the community,
with young people and carers voicing a perception of community-based
clinicians as incapable of managing the complexity of care perceived necessary
to maintain safety.

Additional resources were perceived by all three study group participants
as necessary in order to transition the young person from inpatient back to
community-based care. These requests however if acknowledged by the mental
health service providers in the state in which the studies took place, will result in
major changes to mental health services and delivery.

**Implications of the Findings**

As the shift towards care has moved from hospital to community-based
services, those individuals actually living and working in the community have
received a larger proportion of the burden of care. The findings suggest a desire
for greater collaboration between all parties, for inclusion in decision making
incorporating where care should take place and under what format it should be
offered. Each category of participants has identified a need for greater
collaboration and a significant change in service delivery that is more flexible
and inclusive and appears to be more a continuation of care rather than separated
community and hospital based environments.

According to Rosen, Newton and Barfoot (2003) “Good mental health
care involves balancing and integrating community and hospital care, and
properly resourcing both” (p. 95), whilst Lamb and Bachrach (2001) state that
mental health services should be tailored to the individual’s needs, be culturally
relevant, not restricted by preconceived ideologies, provide individuals with the
right to hospital-based care when it is required, encourage involvement in
treatment decisions and ensure that continuity of care is achieved. It would
appear from the perceptions and reported experiences of the participants from each of the three consumer groups, these recommendations have yet to be realised.

**Changes in service delivery.**

Unique to this study is the participants’ contribution to possible solutions around improvement in service delivery. Referring clinicians request a more open pathway to admission, based mainly on the lack of alternative resources available within the community. Young people and carers suggest a more collaborative approach in service delivery, with greater involvement of community-based clinicians in the inpatient admission of the young person to whom they will be referred to post discharge.

The use of telemedicine, phone link and face time, are examples in which care can be offered, particularly when it is difficult for all parties involved in the care of the young person to be physically present at the one site. Studies that have focussed on video conferencing and internet service delivery for children and adolescents, report consistent support and high satisfaction on the part of the young people, their families and practitioners (Nelson, Barnard & Cain, 2003; Pakyurek, Yellowlees & Hilty, 2010).

Multiple “layers” of service delivery that go beyond the hospital ‘or’ community-based care have been suggested by both young people and their carers. Step down programs, day programs, a segregated inpatient unit that can cater for the different presentations and level of care required and through which the admitted individual can progress, are alternative suggestions to service delivery made by both consumer groups. Currently, this type of multilayered
service delivery is available in other states in Australia through Child and Adolescent Mental Health Services (CAMHS).

These suggestions are not dissimilar to the principles laid out in the model of care (as described in Chapter 1) for young people with mental health needs in the state in which this study was undertaken. Advocating for the mental well-being of young people is a core principal of the model of care. Removing barriers to young people accessing and receiving care is another, along with working in collaboration with all service providers, consumers and carers. Ensuring that programmes offered meet the developmental needs of the young person, is also a core principle within the model of care. Suggestions made by participants however, highlight lack of resources and difficulty in accessing the services that the model of care actively promotes. This results in their perceptions that the needs of young people with mental health problems are often unmet.

**Education around the role of the various services.**

Although all mental health specialists working within the psychiatric services for children and adolescents are accredited within their respective occupations/professions and academically qualified for the task of providing care, experience as well as confidence in working with children and young people at high risk, such as those presenting with chronic self-harm and/or suicidal behaviour, varies considerably amongst clinicians. For clinicians who participated in this study and expressed concern about carrying the risk for young people who voice suicidal ideation, greater support is requested and required.

For young and new recruits to child and adolescent mental health services, knowledge and understanding varies around the role of each of the
services, including what the inpatient unit provides. In order to improve in these areas and enhance skill and knowledge among clinicians, rotations across community and hospital-based services may enhance mutual understanding and respect of each other’s roles, and hopefully result in greater collaboration, with a positive effect on the young people in their care. This suggestion certainly warrants trialling and although accommodated when requested on an individual basis, may prove more effective if considered a mandatory aspect of service delivery. At present, this process occurs for medical students, as well as psychiatric registrars, the latter of whom must incorporate as part of their training, rotations across various service sites. This although benefitting the trainee, has not come without voiced dissatisfaction from consumers such as young people and carers, some of who perceive the rotation of registrars as harmful to developing rapport. Alternatives to this suggestion may include ensuring that community-based clinicians avail themselves to the tele-linked ward rounds and patient meetings, where decisions around care are discussed within the multidisciplinary teams and the referring parties wherever possible. Although this approach has been offered in the past by the inpatient unit in this study, it has not been appropriately prioritised with few community-based teams utilizing the tele-linked facilities on a consistent basis. A change in prioritization might enhance care through a more collaborative and inclusive approach aimed to increase knowledge and greater understanding around the role, function and expectations of each unit/service provider.
Contribution of the Findings

The limited body of published research indicates that understanding the experiences of each of the consumer groups accessing mental health services has been studied sparingly and inconsistently. This is the first project that has specifically targeted consumer groups that have a relationship with the same inpatient unit for children and young people up to the age of 18. It is the first qualitative study that has specifically reported the lived experiences of the three targeted consumer groups around the question of accessibility and suitability of mental health services, and identified specific changes relevant to each of the consumer groups that they believe will enhance continuity in care and facilitate recovery.

The systematic review of the literature undertaken in this thesis has demonstrated how in the past, much of the research undertaken has been survey based and quantitative, focusing on service driven agendas. Whereas it is a worthwhile enterprise to study the effectiveness of programs and interventions offered by specific mental health organizations, it is equally important to understand whether services that currently exist are in fact, from the perspective of the groups that access them, suitable, effective, practical, sufficient, and reflect the desired/expressed needs of the consumer. The qualitative studies identified in the systematic review of the literature were on the whole able to provide greater detail around the lived experiences of child and adolescent psychiatric inpatient care. However, the studies undertaken in this thesis have provided a more in-depth reporting of these experiences and have clearly identified a mismatch between consumer groups’ ideals around what makes for an
appropriate and effective mental health service and what forms of intervention are desirable and perceived as contributing to mental health recovery.

**Methodological Strengths**

The decision to undertake a qualitative study was motivated by the lack of available literature providing rich descriptions of the lived experiences with child and adolescent mental health services, including inpatient units, from the perspective of three specific consumer groups. The rigour and quality of the research and analytical process contributed to the trustworthiness and resonance of the findings.

The methodology used in this study was deemed appropriate due to the nature of the findings elicited, which were able to portray the experiences of the three consumer groups around accessing mental health services. The findings assisted in answering the stated aims and objectives of this body of research. The perspective of referring mental health clinicians, young people admitted to the inpatient unit, as well as carers of young people admitted, ensured that the focus on mental health service suitability, appropriateness and effectiveness, came from the consumers’ perspective and did not reflect service driven needs and ideals. The degree of interest to participate from all three consumer groups was sufficient to allow for saturation to be reached. Saturating participant accounts gave voice to subtle narratives that could not possibly be achieved employing quantitative methods.

During interviews rapport appeared to be established quickly, with the role of the primary interviewer as clinical psychologist in the inpatient unit not interfering with participants’ desire to speak openly and freely around their experiences. Emphasis on confidentiality, ethical considerations and the
informal approach taken during the interviews, contributed to participants’ relaxed and open response style.

**Methodological Limitations**

In all research there will be limitations to research design and methodology. As stated throughout this thesis, although including three separate consumer groups only those currently employed in government funded community-based teams were recruited. The staff from the inpatient unit was excluded from participation, therefore denying their voice in reflecting the viewpoints around referral and admission to the inpatient unit. Similarly, past employees were not approached and comparisons therefore could not be made between previous and current thinking and experiences. Furthermore, self-selection of participants has denied the opportunity to understand the reasons behind non-involvement in the study. Referral to the inpatient unit also occurs from outside of the public sector and inclusion from participants from the private sector may have provided a richer narrative.

Young people not admitted to the inpatient unit but having had experiences with community-based mental health services may also have provided an additional narrative around service accessibility, effectiveness and appropriateness, from their perspective. The same limitations are applied to the carer category of participants who currently had children admitted to the inpatient unit. Narratives from carers whose children were under the care of community-based services may have further contributed to the findings. The triangulation of the results between the three categories of participants however added more credibility and transferability of the results.
Participants from referrer, young person and carer groups in this study have been universal in their desire for their voice to be heard and for consideration to be given to their suggestions for improvement. The findings of this study enable service providers to work in collaboration with all of their stakeholders in reviewing and modifying services that reflect the needs and desires of their consumers and enhances recovery in young people suffering from mental illness.

Regardless of the limitations identified, this study has provided a voice for consumers of mental health services in the state in which this study occurred, in a manner that has not been afforded previously.
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Appendices
APPENDIX 1: INFORMATION SHEETS AND CONSENT FORMS

APPENDIX 1.1: Information Sheet - Referrer

User Satisfaction in a Child and Adolescent In-patient Mental Health Unit

1. The Study: This information sheet is to tell you about a project I, the Senior Clinical Psychologist in [Redacted] Ward am conducting as part of my PhD studies. I will be looking at the expectations and experiences of mental health staff who refer or are likely to refer children and adolescents to [Redacted] Ward at the [Redacted] Hospital.

2. Aims of the Study: An important aim of the study is to identify those aspects of the in-patient admission of children and adolescents that the referrer/potential referrer has found particularly useful, or not and to identify changes that they feel might benefit future stays in [Redacted] ward. The opinions, expectations and experiences of the children and adolescents as well as their parent(s)/carer(s) will also be collated and the information gained from all three groups, compared.

3. Who will be asked to participate?: All metropolitan based [Redacted] units are being asked to take part in this study.

4. Arranging interviews: If you agree to take part in the study, you will be invited by me, Gigetta Salamone-Violi, to arrange an interview time during which general questions about your expectations as well as experiences in referring patients to the in-patient unit will be asked. The interview will run for approximately 60 minutes.

5. Recording of data: All interviews will be audio taped, if you agree to this. The information you provide will be transcribed onto a word document and de-identified. Once fully transcribed, the audiotape will be destroyed. It should be noted that the supervisors of the project, Professors Anna Chur-Hansen and
Helen Winefield will have access to data. They will not have access to any recordings, but they will view de-identified transcripts or notes of interviews.

6. Confidentiality: Your Information will remain confidential except in the case of a legal requirement to pass on personal information to authorised third parties. This requirement is standard and applies to information collected both in research and non-research situations. Such requests to access information are rare: however we have an obligation to inform you of this possibility. Information that is provided however may be included in the final thesis as well as in potential published articles. Anonymity and confidentiality will be maintained at all times.

7. Storage: All information will be retained in secure storage within [redacted] for a period of 30 years beyond completion of the study.

8. Participation and Payment: Your participation is completely voluntary and you can change your mind about participation at any time, including during the interview or even after. There is no payment for participation in the study.

9. Study Approval: This study has the approval of the [redacted] Human research Ethics Committee. I have included the name and contact number of the Executive Officer of the committee incase participants/potential participants wish to discuss the approval process or have any concerns or complaints. I have also included my name and contact details, as well as my supervisors in case you have any questions or anything else you may want to discuss.

Contact Persons:

- Ms Brenda Penny, executive Officer, [redacted] Human Research Ethics Committee; ph:

- Gigetta Salamone-Violi, [redacted], ph:

- Professor Anna Chur-Hansen, Discipline of Psychiatry (University of Adelaide) ph:

- Professor Helen Winefield, Discipline of Psychology (University of Adelaide), ph:
Appendix 1.2: Consent form: Referrer

I have read the attached Information Sheet and agree to take part in the following research project:

<table>
<thead>
<tr>
<th>Title:</th>
<th>User Satisfaction in a Child and Adolescent Psychiatric In-Patient Unit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethics Approval Number:</td>
<td></td>
</tr>
</tbody>
</table>

1. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.

2. I have had the opportunity to discuss taking part in this research project with my Team Manager who has is aware of my involvement in this project.

3. Although I understand that the purpose of this research project is to assess the quality of psychiatric care, it has also been explained that my involvement may not be of any benefit to me.

4. The privacy and confidentiality of any information I provide will be safeguarded as explained in the Participant Information Sheet except where there is a requirement by law for it to be divulged.

5. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.

6. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, or that of my child now or in the future.
7. I agree to the interview being audio recorded. Yes ☐ No ☐

8. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Name: __________________________ Signature: __________________________
Date: __________________________

Researcher/Witness to complete:

I have described the nature of the research to

________________________________________

(print name of participant)

and in my opinion she/he understood the explanation.

Signature: __________________________ Position: __________________________
Date: __________________________
Appendix 1.3: Information sheet – Participant Minor

How satisfied are you with your experiences in [Redacted] Ward?

1. The Study: My name is Gigetta Salamone-Violi. I am the Senior Clinical Psychologist in [Redacted] ward. I am also studying at the University of Adelaide. As part of my studies, I would like to talk to you about your experiences in [Redacted] Ward.

2. Who will be in the study?: I am asking patients in [Redacted] Ward if they want to be in my study. If you want to be part of the study, I will also ask your parents or the person who looks after you if it is ok for you to be in the study. I will also ask Dr [Redacted] if it’s alright for you to participate.

3. What happens in the study?: If you agree to be in the study I will talk to you for about an hour about what it is like on the ward for you and how you are feeling about being here. I will ask you if it is ok to tape record the talk we have, so I can remember it all. But if you don’t want that, there are no problems at all - you can still be in the study without me recording anything.

4. Where else do I get information about you from?: I may need to look in your case notes that we keep here on the ward. I will be looking at information that tells me your date of birth, the date when you were admitted to the ward and the date when you are going to be discharged. I will also look at information that tells me the reason why you were admitted to the ward in the first place.

5. What do you get from being in the study?: I cannot give you anything for being in the study. But, I will be very grateful for your help. The things you tell me might not help you personally, but they might help others in the future, because your thoughts might help us to improve the experiences people have on [Redacted].

6. What happens to the information you give me?: Your information will remain confidential except in the case of a legal requirement to pass on personal information to authorised third parties. This requirement is standard and applies to information collected both in research and non-research situations. Such
requests to access information are rare; however we have an obligation to inform you of this possibility.

What this means is that if you tell me that you want to hurt yourself or someone else, or someone has hurt you, or you have done something that is illegal or someone has done this to you, or forced you to do so, I will need to discuss that with Dr [REDACTED]. What else you/we talk about is only for my study – it is not going to influence your care on the ward. Only you and I will be involved in the interview. I will not be telling anyone else what you said. That is, I will not tell your parents or your guardians or the staff here at [REDACTED] what you have said.

7. Writing a book: When I have finished interviewing people I am going to make summaries of what everyone has said and write a kind of book about it all. Your name will not be in the book and no one will know what you have said. If I have taped our interview, after I have finished writing it up, I will destroy the tape.

8. Data Storage: All of the notes that I take, or interviews that I write up will be kept here on the [REDACTED] in a secure, locked place for up to 30 years beyond completion of the study.

9. What if you change your mind about being in the study?: You can change your mind about being in the study at any time, even during the interview or afterwards and any information that you have given me will not be included. It will be destroyed.

10. Ethics Approval: This study has the approval of the [REDACTED] human Research Ethics Committee. I have included the name and contact details of the Executive Officer of the Committee in case you would like to talk to her about the approval process or if you have any complaints or concerns. Her name is Ms Brenda Penny. I have also included my contact details.

11. Contact Persons:

Ms Brenda Penny, Executive Officer, [REDACTED] Human Research Ethics Committee, [REDACTED]
Gigetta Salamone-Violi, Senior Clinical psychologist, (...

I have two teachers who are helping me with my study – if you wanted to talk to them instead of me (maybe, for example you are unhappy about something I have done), their names are Anna and Helen. Their contact details are:

Professor Anna Chur-Hansen
Discipline of Psychiatry, University of Adelaide

Professor Helen Winefield
Discipline of Psychology, University of Adelaide
Appendix 1.4: Consent Form : Minor

I have read the attached Information Sheet and agree to take part in the following research project:

<table>
<thead>
<tr>
<th>Title:</th>
<th>User Satisfaction in a Child and Adolescent Psychiatric In-Patient Unit</th>
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<td>Ethics Approval</td>
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<td>Number:</td>
<td></td>
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</table>

1. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.

2. I provide consent for the researcher to access my case notes for information relevant to the study and that has been explained to me in the Participant Information Sheet.

3. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.

4. Although I understand that the purpose of this research project is to assess the quality of psychiatric care, it has also been explained that my involvement may not be of any benefit to me.

5. The privacy and confidentiality of any information I provide will be safeguarded as explained in the Participant Information Sheet except where there is a requirement by law for it to be divulged.
6. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.

7. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.

8. I agree to the interview being audio recorded.    Yes □  No □

9. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Name: ______________________ Signature Date: ______________________

Researcher/Witness to complete:

I have described the nature of the research to

_______________________________________________________________

(print name of participant)

and in my opinion she/he understood the explanation.

Signature: ___________________ Position: _______________________
Date: _______________________

223
HUMAN RESEARCH ETHICS COMMITTEE (HREC)

Appendix 1.5: Consent Form: Legal Guardian/Parent

I have read the attached Information Sheet and agree for my child/charge to take part in the following research project:

<table>
<thead>
<tr>
<th>Title:</th>
<th>How Satisfied are you with your experiences in [BLANK] ward?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethics Approval Number:</td>
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</tbody>
</table>

1. I have had the study, so far as it affects my child/charge, fully explained to my satisfaction by the research worker. My consent is given freely.

2. My child/charge was present while the project was explained to us and the opportunity was provided for us to have another family member/friend present.

3. I provide consent for the researcher to access my child’s case notes for information relevant to the study and that has been explained to me in the Participant Information Sheet.

4. Although I understand that the purpose of this study is to assess the quality of psychiatric care, it has also been explained that my child’s/charge involvement may not be of any benefit to them.

5. The privacy and confidentiality of any information that I or my child provides will be safeguarded as explained in the Participant Information Sheet except where there is a requirement by law for it to be divulged.
6. I have been informed that, while information gained during the study may be published, my child/charge will not be identified and their personal results will not be divulged.

7. I understand that my child/charge is free to withdraw from the project at any time and that this will not affect medical advice in the management of their health, now or in the future.

8. I agree to their interview being audio/video recorded. Yes [ ] No [ ]

9. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

**Participant to complete:**

Name: __________________________ Signature: __________________________
Date: __________________________

**Researcher/Witness to complete:**

I have described the nature of the research to

__________________________________________

(print name of participant)

and in my opinion she/he understood the explanation.

Signature: __________________________ Position: __________________________
Date: __________________________
Appendix 1.6: Information Sheet – Adolescent

How satisfied are you with your experiences in _____ Ward?

1. The Study: My name is Gigetta Salamone-Violi. I am the Senior Clinical Psychologist in _____ Ward. I am also studying at the University of Adelaide. As part of my studies, I would like to talk to you about your experiences in _____.

2. Who will be in the study?: I am asking patients in _____ Ward if they want to be in my study. If you want to be part of the study, I will also ask your parents or the person who looks after you if it is ok for you to be in the study. I will also ask Dr. _____ if it’s alright for you to participate.

3. What happens in the study?: If you agree to be in the study I will talk to you for about an hour about what it is like on the ward for you and how you are feeling about being here. I will ask you if it is ok to tape record the talk we have, so I can remember it all. But if you don’t want that, there are no problems at all - you can still be in the study without me recording anything.

4. Where else do I get information about you from?: I may need to look in your case notes that we keep here on the ward. I will be looking at information that tells me your date of birth, the date when you were admitted to the ward and the date when you are going to be discharged. I will also look at information that tells me the reason why you were admitted to the ward in the first place.

5. What do you get for being in the study?: I cannot give you anything for being in the study. But, I will be very grateful for your help. The things you tell me might not help you personally, but they might help others in the future, because your thoughts might help us to improve the experiences people have on _____.

6. What happens to the information that you give me? Your information will remain confidential except in the case of a legal requirement to pass on personal information to authorised third parties. This requirement is standard and applies to information collected both in research and non-research situations. Such
requests to access information are rare; however we have an obligation to inform you of this possibility.

What this means is that if you tell me that you want to hurt yourself or someone else, or someone has hurt you, or you have done something that is illegal or someone has done this to you, or forced you to do so, I will need to discuss this with Dr. [Redacted]. What else you/we talk about is only for my study – it is not going to influence your care on the ward. Only you and I will be involved in the interview. I will not be telling anyone else what you said. That is, I will not tell your parents or your guardians or the staff here at [Redacted] what you have said.

7. Writing a book: When I have finished interviewing people I am going to make summaries of what everyone has said and write a kind of book about it all. Your name will not be in the book and no one will know what you have said. If I have taped our interview, after I have finished writing it up, I will destroy the tape.

8. Data Storage: All of the notes that I take, or the interviews that I write up will be kept here on the [Redacted] in a secure locked place for up to 30 years beyond completion of the study.

9. What if you change your mind about being in the study?: You can change your mind about being in the study at any time, even during the interview or afterwards and any information that you have given me will not be included. It will be destroyed.

10. Ethics Approval: This study has the approval of the [Redacted] Human Research Ethics Committee. I have included the name and contact details of the Executive Officer in case you would like to talk to her about the approval process or if you have any complaints or concerns. Her name is Ms Brenda Penny. I have also included my contact details.

11. Contact Persons:

Ms Brenda Penny, Executive Officer, [Redacted] Human Resource Ethics Committee;
I have two teachers who are helping me with my study – if you wanted to talk to them instead of me (maybe, for example you are unhappy about something I have done), their names are Anna and Helen. Their contact details are.

Professor Anna Chur-Hansen
Discipline of Psychiatry, University of Adelaide

Professor Helen Winefield
Discipline of Psychology, University of Adelaide
Appendix 1.7: Consent Form: Adolescent

I have read the attached Information Sheet and agree to take part in the following research project:

<table>
<thead>
<tr>
<th>Title:</th>
<th>User Satisfaction in a Child and Adolescent Psychiatric In-Patient Unit</th>
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</thead>
<tbody>
<tr>
<td>Ethics Approval Number:</td>
<td></td>
</tr>
</tbody>
</table>

1. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.

2. I provide consent for the researcher to access my case notes for information relevant to the study and that has been explained to me in the Participant Information Sheet.

3. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.

4. Although I understand that the purpose of this research project is to assess the quality of psychiatric care, it has also been explained that my involvement may not be of any benefit to me.

5. The privacy and confidentiality of any information I provide will be safeguarded as explained in the Participant Information Sheet except where there is a requirement by law for it to be divulged.
6. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.

7. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.

8. I agree to the interview being audio recorded. Yes ☐ No ☐

9. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Name: ___________________________ Signature: ___________________________
Date: ___________________________

Researcher/Witness to complete:

I have described the nature of the research to

__________________________________________________________

(print name of participant)

and in my opinion she/he understood the explanation.

Signature: ___________________________ Position: ___________________________
Date: ___________________________
Appendix 1.8: Information Sheet – Adult

How satisfied are you with your experiences in  [ ] Ward?

1. The Study: My name is Gigetta Salamone-Violi. I am the Senior Clinical Psychologist in [ ] Ward. I am also studying at the University of Adelaide. As part of my studies, I would like to talk to you about your/your child’s/charge’s experiences in [ ].

2. Who will be in the study?: I am asking patients, their parents/carers in [ ] Ward if they want to be in my study.

3. What happens in the study?: If you agree to be in the study I will talk to you for about an hour about what it is like on the ward for you and your child/charge. I will ask you for permission to tape record the talk we have. But if you don’t want that, you can still be in the study without me recording anything.

4. Where else do I get information about you from? I may need to look in your child’s case notes for information such as their date of birth, the date they were admitted to the ward and the date of their anticipated discharge. I will also look for information that tells me the reason why they were admitted to the ward in the first place.

5. Participation and Payment: There is no payment for being in the study. But, I will be very grateful for your help. The things you tell me might not help you personally, but they might help others in the future, because your thoughts might help us to improve the experiences people have on [ ].

6. What happens to information provided?: Your information will remain confidential except in the case of a legal requirement to pass on personal information to authorised third parties. This requirement is standard and applies to information collected both in research and non-research situations. Such requests to access information are rare: however we have an obligation to inform you of this possibility.
What we talk about for my study is not going to influence your child’s/your care on the ward.

7. Publications: When I have finished interviewing people I am going to make summaries of what everyone has said and write them down as part of my thesis. I will then destroy the audio tape. You should be aware that my supervisors will be able to view the written transcripts from the interview but only after all information has been de-identified. The results might be published at a later date but your name and that of your child will not appear/be published and no-one will know what you have said.

8. Storage: All information that I have recorded will be kept in locked storage for a period of up to 30 years beyond completion of the study.

9. Changing your mind: You can change your mind about being in the study at any time, even during the interview or afterwards and any information that you have given me will not be included. It will be destroyed.

10. Ethics approval: This study has the approval of the Human Research Ethics Committee. I have included the name and contact details of the Executive Officer of the Committee in case you would like to talk to her about the approval process or if you have any complaints or concerns. Her name is Ms Brenda Penny. I have also included my contact details.

11. Contact Persons:

Ms Brenda Penny, Executive Officer, Human Research Ethics Committee, ph:

Gigetta Salamone-Violi, Senior Clinical Psychologist, ward, ph: 08
I have two professors who are helping me with my study – if you wanted to talk to them instead of me (maybe, for example you are unhappy about something I have done), their names are Anna and Helen. Their contact details are:

Professor Anna Chur-Hansen, Discipline of Psychiatry (University of Adelaide),

Professor Helen Winefield, Discipline of Psychology (University of Adelaide)
HUMAN RESEARCH ETHICS COMMITTEE (HREC)

Appendix 1.9 : Consent Form: Adult

I have read the attached Information Sheet and agree to take part in the following research project:

<table>
<thead>
<tr>
<th>Title:</th>
<th>How satisfied are you with your experiences in Ward?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethics Approval Number:</td>
<td></td>
</tr>
</tbody>
</table>

1. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.

2. I provide consent for the researcher to access my child’s case notes for information relevant to the study and that has been explained to me in the Participant Information Sheet.

3. Although I understand that the purpose of this research project is to assess the quality of psychiatric care, it has also been explained that my involvement may not be of any benefit to me.

4. I have been given the opportunity for a family member or friend to be present while I have the project explained to me.

5. The privacy and confidentiality of any information I provide will be safeguarded as explained in the Participant Information Sheet except where there is a requirement by law for it to be divulged.

6. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.
7. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, or that of my child now or in the future.

8. I agree to the interview being audio recorded. Yes ☐ No ☐

9. I would like a copy of the transcribed interview? Yes ☐ No ☐

10. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

**Participant to complete:**

Name: ___________________ Signature: ___________________

Date: ____________________

**Researcher/Witness to complete:**

I have described the nature of the research to

________________________________________________________

(print name of participant)

and in my opinion she/he understood the explanation.

Signature: ___________________ Position: ___________________

Date: ____________________
Appendix 2: Paper 3

FEATURE ARTICLE

‘I don’t want to be here but I feel safe’: Referral and admission to a child and adolescent psychiatric inpatient unit: The young person’s perspective

Gigetta M.L. Salamone-Violi, Anna Chur-Hansen and Helen R. Winefield
School of Psychology, The University of Adelaide, Adelaide, South Australia, Australia

ABSTRACT: Early and appropriate intervention can assist children and young people manage their mental illness and prevent it becoming a long-term condition. However, satisfaction with mental health services can influence the level of engagement individuals are willing to participate in beyond the time of the initial contact or hospitalization. A qualitative design was used to identify and understand the experiences of the admission process for young people referred to the sole psychiatric inpatient unit in one Australian state for children up to the age of 18 years. Eleven young people participated in semistructured interviews that were audiotaped, transcribed, and coded. Interview data were examined through thematic analysis. Satisfaction with the inpatient experience was influenced by whether or not young people experienced a sense of connection with staff or other patients on the ward. The ability of nursing staff in identifying and catering to the individual needs of young people in their care facilitated feelings of safety, security, and acceptance, and contributed to the young person’s desire to remain engaged in treatment post-discharge. This research supports the shift towards perceiving patient satisfaction as a separate entity from service delivery and quality, with some participants able to voice dissatisfaction about the lack of services, while reporting overall satisfaction with the inpatient experience.

KEY WORDS: child and adolescent, inpatient, psychiatric, satisfaction.

INTRODUCTION

In most Western countries, individuals with a mental illness, including children and young people, have basic rights regarding decisions about where and what type of care they should receive. However, many young people with mental illness do not voluntarily engage in professional help-seeking behaviour (Yap et al. 2013). Family or friends, the family doctor, or the school counsellor are often the ‘treatment’ choices preferred by young people (Rickwood et al. 2007; Sawyer et al. 2000). Shame, stigma, embarrassment, and rejection, or being judged poorly by those from who help is sought, are possible reasons for this (Yap et al. 2013).

There are occasions when the admission of young people to a psychiatric inpatient facility is warranted, and ideally access to such services would be achieved on a voluntary basis. However, particularly in the case of need for treatment and the potential for danger towards self and/or others (Kaitila-Heino 2010), treatment can be enforced.

When either voluntary or compulsory intervention results in a negative experience, an individual might resist treatment again as required at a later stage. Intervention,
although considered necessary at the time, might have resulted in a less than satisfactory outcome. A positive experience could result in a willingness to continue treatment beyond the time of the initial contact or hospitalization (Boyer et al. 2009; Bunge et al. 2014; Clark & Winsor 2010). Therefore, determining patient satisfaction is an essential step towards providing effective and appropriate care.

With greater understanding of mental illness and treatment, and with the drive towards consumer participation at all levels, the input of young people on issues, such as consumer satisfaction, is now sought. The United Nations Convention on the Rights of the Child (1989) gives support to the idea that young people have the right to be involved in treatment decisions that affect them. This includes treatment regarding their mental health. Understanding patients’ perspectives and experiences of care, and acting on those findings through models of care, might help to address issues of engagement and continuation of treatment for young people with mental illness (Boyer et al. 2009; Bunge et al. 2014; Clark & Winsor 2010).

According to Gill and White (2009), while identifying levels of patient satisfaction is a highly desirable health outcome, it remains a poorly-defined concept with no one universally-accepted definition. It is also difficult to measure, possibly due to the multifaceted nature of satisfaction. Consequently, questionnaire-based research has often been employed, largely because it is a quick, easy, and less expensive method of gathering data. Questionnaire-based research is not without its problems. Questions are often service generated, focusing on aspects of care delivery that might not have the same degree of importance to the consumer. Similarly, and possibly the greatest criticism, is the inability of questionnaire-based research to describe the actual experiences of the individual regarding their care and how that in turn influences satisfaction (Webster et al. 2012).

Within public mental health services for children and adolescents, consumer satisfaction has not been studied extensively (Biering 2010). Studies specific to child and adolescent perceptions of inpatient care are even more limited (Biering 2010). From these studies however, three universal components relevant to adolescent satisfaction with mental health services have been identified. They include: (i) satisfaction with the environment and organization of the services (Groessoehme & Gerbetz 2004); (ii) satisfaction with the adolescent-caregiver interaction, especially regarding the continuity of care; that is, having the same staff member involved for the duration of the treatment (Marriage et al. 2001); and (iii) satisfaction with treatment outcomes experienced as positive changes in thought, feelings, and skill acquisition (Geanellos 2002; Lee et al. 2006).

Areas of concern regarding standardization, low reliability, and questionable validity of the instruments used (Biering 2010; Hawthorne 2006) make the generalization of results from questionnaire-based research difficult. In qualitative studies, of which there are few, asking participants what they perceive as a necessary change to ensure continuity in care has rarely occurred. Clarifying the aspects of the inpatient admission that the young person identifies as satisfactory is an important area to explore. The advantage of applying a qualitative research approach is that it provides young people with the opportunity to describe all aspects of their admission experience, including referral and discharge. Open-ended interviews also allow for young people to make suggestions about changes or improvements in care relevant to the setting in which they receive that care, therefore, going beyond that which can be achieved by standard questionnaires.

This type of research adds valuable information to the literature that looks to explore aspects of care that are beneficial to the young person and contributes to their continuing in treatment post-discharge. The information derived could be unique to the site in which it is being undertaken. It is however, a process that can be applied across all child and adolescent mental health treatment settings, eliciting information that can influence policy, procedures, and models of care. The aim of the present study was to identify and understand the experiences of the admission process for young people referred to an inpatient unit in one Australian state, for children up to the age of 18 years who have a psychiatric illness.

METHODOLOGY

Approval was sought and received from the appropriate human research ethics committee.

Recruitment

A purposeful sampling technique was used for participant recruitment. Participants were children and adolescents admitted to an Australian inpatient unit in which the study was conducted. The unit was the only one of its type in the state. On admission to the ward, young people and their carers were informed of the study, and subsequent to initial consent to participate, were approached again at the end of their admission stay by the clinical psychologist (first author), where intent to participate was confirmed. The chief psychiatrist on the inpatient unit provided input regarding suitability (mental state evaluation) for
participation. Potential participants were included in the study only if the interviewer had no current working (i.e. therapeutic) relationship with the young person referred to the inpatient unit.

Procedure

Consent
An information sheet outlining the aims and purpose of the study was prepared for recruitment of participants. Young people under the age of 16 years and their carers were asked to give their written consent for participation in the study. Young people 16 years and older were able to provide consent without accompanying signed consent from their carer. However, all carers of participants 16 years or older included in this study were aware of their child’s participation. Written consent was obtained prior to the interview being conducted, on the scheduled day of discharge.

Participants
Eleven young people participated in the study; six males and five females. The age of the participants ranged from 15 years to 17 years. The diagnoses on discharge of the participants included depression, adjustment disorder, suicidal ideation/self-harm, and situational crisis, with a length of stay ranging from 4 days to 15 days. Four of the participants were admitted under an involuntary treatment order (ITO).

Data collection
Interviews
Interviews were conducted between March and November 2014. Open-ended, semistructured interviews ranging from 15 min and 28 s to 50 min and 10 s were conducted and audiotaped with participant consent, and were transcribed by the interviewer. All interviewees were aware of the interviewer’s position on the inpatient unit as a clinical psychologist, and reassurance regarding anonymity was repeated at time of consent and at the beginning of the interview. The interviewer was not involved in the clinical care of any participant.

Each interview commenced with the broad question: ‘Can you tell me about your experiences in being admitted to the inpatient unit?’. Additional interview questions were guided by the interviewee’s responses and were also complemented by previous participants’ responses. An audit trail was kept during data collection and data analysis. The audit trail guided the decision to end sampling when data saturation was reached. Saturation refers to the point at which collected data are repetitive and are not conducive to new information (Morse 1995).

Data analysis
Interview data were analysed thematically following the guidelines of Braun and Clarke (2006; 2013). This method of analysis involves the identification of themes within and between participants’ transcribed interview data.

The six stages of thematic analysis applied in the present study were: (i) data familiarization; (ii) code generation; (iii) theme search; (iv) theme review; (v) theme definition and naming; and (vi) report preparation (Braun & Clarke 2006; 2015). All authors read the transcribed interviews, with the first author generating initial codes for the first interview, which were refined and recoded with input from all authors. The first author coded subsequent interviews. Emerging themes were then defined and redefined among all authors until the main themes were established. Checking of the themes by both the second and third authors enhanced methodological rigor and trustworthiness (Tracy 2010). Participant validation of the transcripts was attempted, with no respondents requesting a viewing of their transcripts.

RESULTS
The themes and subthemes extracted from the interview transcripts are summarized in Table 1.

Three overarching themes regarding each young person’s experiences with the inpatient admission emerged: emotional response to the inpatient experience, experiences of the admission itself, and outcomes.

Emotional response to the inpatient experience
Participants described positive or negative feelings, depending on whether they had initially agreed to the inpatient admission. Participants admitted under an ITO were most likely to report negative feelings, but did not exclusively. Participants’ initial responses to being admitted to the psychiatric inpatient unit were categorized under three subthemes: acceptance, powerlessness, and fear of the unknown.

Acceptance
Participants’ responses under this theme indicated a desire for intervention:

I dunno if I was hoping it would happen, I just, well I just wanted to feel better and I needed help, so yeah, I guess it was alright. (Participant 11, 17-year-old male)

Powerlessness
Participants expressed the perception that admission was beyond their control and a consequence of decisions made by others:
### TABLE 1: Summary of overarching themes and subthemes

<table>
<thead>
<tr>
<th>Overarching themes</th>
<th>Subthemes</th>
<th>Additional themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional response to the inpatient experience</td>
<td>• Acceptance</td>
<td>&gt; Confinement</td>
</tr>
<tr>
<td></td>
<td>• Powerlessness</td>
<td>&gt; Individual therapy</td>
</tr>
<tr>
<td>Experience of the admission itself</td>
<td>• Fear of the unknown</td>
<td>&gt; Group therapy</td>
</tr>
<tr>
<td></td>
<td>• Interaction with others (staff and other people)</td>
<td>&gt; Family meetings</td>
</tr>
<tr>
<td></td>
<td>• Environment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Therapy</td>
<td></td>
</tr>
<tr>
<td>Outcomes</td>
<td>• Containment</td>
<td>&gt; Information</td>
</tr>
<tr>
<td></td>
<td>• Advocacy and awareness</td>
<td>&gt; Ward activities</td>
</tr>
<tr>
<td></td>
<td>• Mental state</td>
<td>&gt; Discharge planning</td>
</tr>
<tr>
<td></td>
<td>• Desired changes</td>
<td></td>
</tr>
</tbody>
</table>

I was in my bed. I didn’t want to, I didn’t want them there, but they picked me up and carried me to the ambulance. (Participant 1, 15-year-old female)

**Fear of the unknown**
Participants’ expectations about what admission to the inpatient unit would entail were not always clear and contributed to feelings of uncertainty, including with regards to acceptance by other patients:

I didn’t know what to expect. I didn’t know if people were going to like me being there and like me as a person. (Participant 2, 15-year-old female)

**Experience of the admission itself**
This theme was representative of the perceived quality of care offered to the young person during the admission. Participants often compared the care they received in the inpatient unit with the quality of care received in the community. Participants’ perception of their inpatient experience was represented by three subthemes: interaction with others (staff and other patients), environment, and therapy.

**Interactions with others: staff**
Participants expressed high expectations of the inpatient staff in both levels of expertise, as well as degree of involvement in care. Participants who were reluctant for admission voiced an expectation of greater levels of interaction with nursing staff in particular, that was not fulfilled:

The nurses are always busy. It’s like it’s a bother to ask them for anything. You always have to wait and sometimes they forget about you. (Participant 11, 17-year-old male)

However, participants who were more accepting of the inpatient admission described a connection towards staff that they perceived lacking with others outside of the hospital environment:

Outside of the ward, like if I’m back at school and I’ve tried to tell my teachers how I’m feeling, they don’t understand, they don’t really listen, but they do here, they get it. (Participant 3, 15-year-old female)

These participants also reported a perception that the inpatient staff were more capable than their community-based mental health clinicians to deal with the serious or complex case presentations:

I don’t think she got it, and I really didn’t, you know, connect with her. Besides, I don’t know if she can handle it. It would freak her out and she’d probably have just sent me here anyway. (Participant 6, 16-year-old male)

**Interaction with others: patients**
How young people related to their peers influenced the young person’s perception of the appropriateness of their stay on the unit. This in turn contributed to the overall level of satisfaction with the inpatient experience. Young people who did not seek out admission described feeling frightened of other patients who they considered more unwelcome than themselves, leading to a sense of not belonging:

I don’t see things that aren’t there. I make sense, she doesn’t. I don’t want to be here. I just don’t like getting out of bed so what? (Participant 1, 15-year-old female)

When young people experienced some form of connection with peers, however, it was this relationship that they perceived responsible for making the inpatient experience a positive one:

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It's the other kids that make it work; that gives you hope. (Participant 10, 17-year-old male)

Environment
The subtheme 'environment' included the participants’ perceptions of the physical environment and how it impacted on their mental health. Participant responses highlighted how discontent or frustration about certain aspects of the inpatient unit could be acknowledged, without it affecting their overall perception of satisfaction with the inpatient experience. The physical environment of the inpatient unit was described by participants in negative terms regarding the lack of accessibility to an outdoor area within hospital grounds:

We don't have a balcony or outside area though. (Participant 7, 17-year-old male)

Confined was one aspect of the environment that participants highlighted, in discussing the restrictions that occur within a locked environment:

The whole time I was here for awhile I was thinking that, I don't know what the word is, confined maybe in a sense, because you know sometimes they lock the doors because some people are here against their will, and I felt confined. (Participant 10, 17-year-old male)

However, participants also acknowledged some benefit to them from these restrictions. They described the physical aspect of the ward as a place of safety, where the possibility of enacting on suicidal thoughts was reduced to a remote possibility:

Of course being here keeps me safe, for a suicidal person, it keeps me safe. (Participant 10, 17-year-old male)

Therapy
This subtheme included participant perceptions about the therapies that were provided to them during their admission. Therapy highlighted how individual needs of participants, as well as the degree of acceptance about being on the inpatient unit, influenced their perception of the usefulness of the type of therapy or intervention offered. Additional themes included individual therapy, group therapy, and family meetings.

Individual therapy Participants who viewed the inpatient unit as a superior source of understanding and staff skill over that available within the community also perceived the inpatient unit to be the best place to commence or continue individual therapy:

They get me here, so here is where I should get help so that I can cope outside. I know it's not the real world, but it's not as scary, so I think I would feel better, accept more help if it came from here where I truly think people understand. (Participant 10, 17-year-old male)

However, participants who were reluctant for admission were also reluctant to accept any intervention:

I . . . don't need other therapy 'cause I have my psychiatrists. (Participant 3, 15-year-old female)

Group therapy Participants reported a lack of clinician-led, therapy-based group sessions. However, this perceived gap in service delivery was not viewed unfavourably:

When you are feeling really bad, it's good not to talk sometimes. I've done group work before and it never works 'cause that's when I don't want to talk, then none of the other kids want to talk either, so nah, maybe when I start to feel better, but even then, I prefer one on one. (Participant 4, 16-year-old male)

Family meetings Favourable remarks by participants were made about the usefulness of family meetings, which the participants reported as difficult to replicate within the community:

My parents are divorced and they hate each other. They don't even want to be in the same room together, so here on the ward they have to, they have to listen and talk. (Participant 8, 16-year-old female)

Outcomes
This theme included participant perceptions of personal and system-based changes. On a personal level, participants described how the inpatient unit impacted on their mental state and recovery. On a systems level, participants reflected on aspects of the inpatient experience they perceived as requiring change or modification. The theme 'outcomes' included the following subthemes: containment, advocacy and awareness, mental state, and desired changes.

Containment Participants expressed a perception of the inpatient unit as a place where they could not easily engage in self-harm and suicidal behaviour:

At home . . . it exhausts me. I have to keep me and other people safe. Here I don't have to worry about myself. (Participant 6, 16-year-old male)

Advocacy and awareness Participants perceived the inpatient unit as a venue for them to speak through staff advocates to alert others of the difficulties and intensity of their distress:
It's good that the staff here at least understand and can help my parents understand as well. (Participant 9, 17-year-old male)

Mental state
Participants reporting a perception of improvement made reference to changed feelings or thoughts that were present at admission:

My calming down, I'm more calm, not going off at people, and talking to my psych who comes in to see me on the ward has been good. (Participant 3, 15-year-old female)

Participants were less likely to report the inpatient experience as beneficial if there was a perception of little change or if expectations on admission had not been met:

They don't talk to you; they just pretty much leave you alone or send you down to school, and there's nothing to do except talk to the other kids. So how am I supposed to get better? They don't let you stay long enough. I didn't get any medication, so what's the point? (Participant 11, 17-year-old male)

Desired changes
This subtheme included aspects of the inpatient admission that were identified by participants as unsatisfactory and requiring modification or change. Additional themes included: information, ward activities, and discharge planning.

Information Participants reported a lack of available information explaining the nature of the inpatient admission prior to entering the unit. Lack of information was particularly problematic for participants who were admitted to the ward after normal working hours with minimal staff and other patients already asleep, eliciting feelings of fear, uncertainty, and discomfort:

I mean, I didn't even know where I was, and then I was expected to just go to sleep and speak to someone in the morning. I thought someone would have explained more then. I didn't even know who it was in the other bed; it was weird. (Participant 11, 17-year-old male)

Ward activities Although the absence of therapist-led group sessions was not criticized, the lack of or minimal ward-based activities, such as art and craft, cooking, and outdoor-based activities, resulted in a negative perception of the inpatient experience:

It's really boring. If I was here on my own, it would be a hell hole. There's not much to do. (Participant 4, 16-year-old male)

Discharge planning Participants alluded to cooperative decision-making as influencing their perception of the inpatient experience, particularly with regards to discharge. Participants who were, from the onset of admission, more open to inpatient care were also more likely than those who were not to seek out extended stay:

I need to stay longer, so I won't hurt anyone and I'll learn how to trust myself and ignore these feelings. (Participant 6, 16-year-old male)

In the absence of a longer length of stay, participants identified graduated discharge from the unit as a satisfactory alternative:

Maybe during that time I would try having some leave, see if it's OK, then have more leave, go see some friends, do what I do normally, maybe stay overnight and then go after that. (Participant 4, 16-year-old male)

DISCUSSION
The present study contributes to the body of research that supports the shift towards perceiving patient satisfaction as a separate entity from service delivery and quality. The qualitative nature of this research has enabled young people to describe their individual experience of admission and explain aspects of it that contributed to satisfaction and the desire to continue in care.

Participants who were less willing for the admission experience described strong negative emotions, such as fear, anger, and concern, about how they themselves would be viewed by staff and other patients. They also expressed concern about whether they would be judged or accepted. These participants described a perception of existing inpatients’ problems as far more serious than their own, contributing to the perception of admission as being unwarranted. A lack of connection to any aspect of the inpatient experience was further exemplified by participants' negative descriptions of care offered within the inpatient unit. Conversely, participants who were less oppositional to the idea of admission perceived the inpatient admission as an opportunity to regain mental health in a place where assistance, support, and understanding were experienced and contributed towards recovery.

In line with previous research, (Marriage et al. 2001) participants in the present study identified the adolescent–caregiver interaction as aspects of care contributing to patient satisfaction. Participants accepting of admission viewed the inpatient referral as a means of access to highly-skilled and experienced clinicians on whom they could unburden the responsibility of keeping
themselves safe. This was something they perceived that could not be achieved in the community. The 24-hour care, rather than care specifically with one staff member for the duration of the stay, as previous research suggested (Marriage et al. 2001), was considered a positive experience. Young people admitted to the ward required different types and levels of intervention. The ability of the nursing staff to differentiate and advocate for the type of intervention the young person required and desired influenced the overall perception of the inpatient stay.

Patient satisfaction was found in previous research to be linked to the environment of the hospital unit (Groessslehme & Gerbetz 2004). In this particular study, participants were able to differentiate between unsatisfactory aspects of the ward, such as lack of open space and access to an outside area, from the benefits of being in a locked ward where means and access to modes of self-harm would be difficult. For this group of participants, a lack of services or amenities alone was not sufficient to determine patient satisfaction. Instead, aspects of care that the young people prioritized as important were an influencing factor.

For the participants, family meetings, with an emphasis on advocacy and support, were preferred instead of traditional therapies. Furthermore, fun-based activities were the preferred form of group activity sought by both categories of participants in this study. Nursing staff who were able to provide these types of activities for the young people in their care were instrumental in influencing the young person’s overall perception of their inpatient stay.

Previous research has cited rejection or being judged poorly by those from whom help was sought as reasons why young people might not seek out help (Yap et al. 2013). To a degree, these reasons appeared to apply to participants in the present study who did not believe that hospitalization was merited in their case. However, participants who were more open to the idea of admission reported perceptions of acceptance and non-judgment with other young inpatients on the unit with whom they had achieved some connection. This perceived connection was one of the most satisfying aspects of the inpatient admission and the driving force towards seeking extended stay and continued connection with both peers and treatment.

Previous studies have linked satisfaction with treatment outcomes, particularly with reported changes in cognitions and the perception of skill development (Geannellos 2002; Lee et al. 2006). Participants in the present study acknowledged positive or no change in feelings, thoughts, or behaviours, depending on their category regarding perceptions about admission. However, a lack of change or partial improvement did not necessarily result in dissatisfaction with the inpatient experience, if other needs already referred to had been met.

How discharge was determined and executed appeared to influence perceived usefulness of the inpatient experience, with planned and graduated discharge that maintains a connection to the unit being most favourably perceived. Young people who perceived benefit from the admission, and were satisfied with the discharge process, were also most likely to desire continuity.

Implications and recommendations

A strong sense of connection to other patients and with staff, and a belief that individual needs with regards to therapy and other interventions could be recognized and met, were aspects of care that the participants in the present study identified as satisfying. Willingness and a desire to remain engaged in treatment were perceived as more likely to occur as a consequence. These findings have implications for models of care.

As mental illness varies in type and complexity, a stand-alone and singular dedicated inpatient unit for children and adolescents might not have the capacity to meet the needs of everyone requiring inpatient care. A ‘step up and step down’ complex, where young people can move through depending on the nature and seriousness of their mental illness, could reduce the degree of distress initially experienced by unwilling young people when admitted to the inpatient unit. This would also address the issue of graduated discharge requested by young people who have accepted the inpatient admission, but still believe they require a greater duration of care. Furthermore, day programmes offered by inpatient units might assist community-based clinicians who identify the need for further, more intense treatment for the young people in their care. In the past, hospitalization might have been the only option.

When admission is considered the most appropriate treatment option, modifications to the way in which it is approached could reduce the degree of distress some individuals report. Nursing staff who spend the majority of the time with the young person admitted to the inpatient unit play a very large role in both preparing the young person for admission and identifying with them the individual needs that can be addressed during the inpatient stay. This includes the form of intervention and therapies that are most likely to engage the young person. Alternate therapies, such as art and music, might address the young person’s desire for treatment in an environment that offers opportunities to connect with others through ‘fun-based’ activities. Employing staff trained in
these therapies or providing training opportunities for existing staff can enhance the overall 'package of care' provided to young people. When attempting to include young people in their own care delivery with the hope of encouraging their adherence to treatment post-discharge, these considerations are crucial.

**Strengths and limitations**

The findings of the present study expand on previous research on patient satisfaction in child and adolescent mental health units. A strength of the present study is the reporting of opposing perceptions of care based largely on the young person's willingness or reluctance for admission to the inpatient unit, which has not been identified in previous research. A further strength has been the ability to derive from participants an insight into changes that could improve the likelihood of continued engagement with young people in mental health treatment.

The present study has some limitations. The single site from which participants were recruited potentially limits the generalizability of the findings. Furthermore, the findings are based on the perspectives of a select group of individuals aged 15–17 years of age and who were not admitted with a diagnosis of psychosis. The inclusion of younger individuals, as well as those who had been admitted with severe mental illness, might have provided a different perspective.

**REFERENCES**


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Appendix 3: Paper 4

Salamone-Violi, G., Chur-Hansen, A. & Winefield, H. (2016). In this day and age why is it still so hard to find the right type of help? Carers’ perspectives around child and adolescent mental health services. A qualitative study.

*Advances in Mental Health*, http://dx.doi.org/10.1080/18387357.2016.1195697
In this day and age why is it still so hard to find the right type of help? Carers’ perspectives regarding child and adolescent mental health services: a qualitative study

Gigetta M. L. Salamone-Viol, Anna Chur-Hansen & Helen R. Winefield

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To link to this article: http://dx.doi.org/10.1080/18387357.2016.1195697

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Gigetta M. L. Salamone-Violi, Anna Chur-Hansen and Helen R. Winefield

School of Psychology, The University of Adelaide, Adelaide, Australia

ABSTRACT
Objective: To identify perceptions and experiences of children and young people accessing mental health services in one state in Australia from the perspective of their carer.
Method: Semi-structured interviews were employed in this qualitative study with 11 carers of children admitted to a child and adolescent psychiatric inpatient unit. Interviews were audiotaped, transcribed and coded. Thematic analysis following the guidelines of Braun and Clarke [(2013). Successful qualitative research: A practical guide for beginners. London: Sage] was applied to the interview data. This method of analysis includes: data familiarisation, code generation, theme search, theme review, theme definition and naming and report preparation.
Results: Three overarching themes emerged: experiences prior to admission; expectations about admission and the inpatient experience. Contrary to previous research, satisfaction with mental health services was found to be greater in inpatient units. Dissatisfaction with community-based mental health services focussed on poor accessibility, long waiting times, exclusion from therapy sessions and incomplete assessments that often warranted additional specialist intervention. Carers living in country, rural and remote regions of the state were most vocal in dissatisfaction with community-based services.
Conclusions: Carer perceptions of the inpatient unit as the most desirable and appropriate form of mental health intervention for their child go against the current shift in treatment focus to provide care in the least restrictive environment, that is, the community. This has implications for future service delivery and design and supports research that has highlighted carer satisfaction to being closely linked to factors other than clinical improvement.

Introduction

Over the last few decades, advances in mental health have meant that treatment for people suffering from mental illness including children and adolescents is favoured to occur in the least restrictive environment, that is, the community, with inpatient admissions restricted to brief treatment focussing on crisis stabilisation, assessment and discharge planning.
(Hopkins, Loeb, & Fick, 2009; Moses, 2011). This has meant that for carers of young people suffering from mental illness, the burden of care for their child lies heavily on their shoulders and with community-based mental health services.

Research about child and adolescent mental health services from the perspectives and experiences of carers of young people with mental illness is limited (Gill, Butler, & Pistrang, 2016). That which does exist suggests that the impact on carers and the family in coping with the range of mental health-related problems faced by their children can be quite devastating, often exacerbating existing problems and tension. Carers report feelings of loss and grief about the mental illness diagnosis, as well as physical and emotional exhaustion in living with and managing the condition (Delaney & Engels-Scianna, 1996; Gopalan et al., 2010; Mohr & Regan-Kubinski, 2001). Seeking help for the young person can further exacerbate these feelings and concerns with carers often unsure and fearful of how their child will be treated and cared for. The appropriateness of the treatment as well as the stigma associated with the treatment itself are also sources of concern (Askey, Holmshaw, Gamble, & Gray, 2009; Mukolo, Hefflinger, & Wallston, 2010).

How satisfied a carer is with the mental health services offered to their child is likely influenced by how well their own concerns have been addressed. How well their concerns have been addressed is also likely to influence how actively the carer encourages and supports their child’s connection and continuity with mental health services (Azzi-Lessing, 2013; Rey, Plapp, & Simpson, 1999; Scharer, 2000) It is imperative, therefore, that in service delivery, the involvement of carers occurs.

Previous research has identified the type of involvement carers find satisfactory when seeking assistance for their child. An effective therapeutic alliance between parents’ and mental health providers’ practical and emotional support, education about the illness and treatment and affirmation of the carer’s role and impact on the child have all been linked to carer satisfaction (Brinkmeyer, Eyberg, Nguyen, & Adams, 2004; Crow et al., 2002; Gavidia-Payne, Littlefield, Hallgren, Jenkins, & Coventry, 2003; Gerson et al., 2009; Jakobsen & Severinsson, 2006; Pinfold et al., 2004; Scharer, 2002; Tarico, Benson, Trupin, & Forsyth-Stephens, 1989). Feeling disrespected or judged poorly by the mental health service provider, lack of recognition of the level of expertise in their child’s problems and needs and perceived hostility toward parents'/carers’ desire to be involved in the treatment of their child can all contribute to carer dissatisfaction. Dissatisfaction has also been found to be greatest across inpatient settings (Ewertzon, Lutzen, Svensson, & Andershed, 2010; Geraghty, Mccann, King, & Eichmann, 2011).

In Australia, surveys have become popular means of capturing consumer experiences in service delivery. They have become the tool often utilised in determining advances that have been made and changes that may be required. Surveys, however, are often service driven and often do not allow the respondent to describe the actual experiences of care and how that in turn influences satisfaction (Webster, Gallaher, Lopez, Brown, & Evans, 2012). In order to overcome shortcomings inherent in survey style measures, Lelliott et al. (2001) suggested that it was important to listen to what the consumer wants or needs because service providers cannot assume to know what the consumer outcomes are of importance to service users. Qualitative studies are in this instance preferable, as they are able to provide in-depth information about the lived experience of consumers that can be used to both evaluate the service, identifying its strengths and weaknesses from different perspectives, as well as influence future service type and delivery (Alvarez Del Arco, Rodriguez,
Sanchidrian de Blas, Alejos, & Pia Mestre, 2012; Jones et al., 2009). It is a process, therefore, that can be easily replicated across treatment settings and across different consumer groups.

This study examines the expectations, perceptions and experiences of carers about accessing mental health services for their child, including inpatient admission. A qualitative approach applying an interview format guided by open-ended questions was selected for this study. This approach enhances the depth and breadth of information beyond that which fixed format standardised questionnaires are likely to achieve (Alvarez et al., 2012). It also reduces researcher bias and allows for greater focus on what the consumer views as relevant and necessary for change (Shenton, 2004).

Child and adolescent mental health services in this study refers to the community-based services available within the state (both country and metropolitan) in which this study was conducted. It includes the sole inpatient psychiatric unit for children and young people up to the age of 18 years.

**The inpatient unit**

The inpatient unit in this study provides comprehensive and specialised care and support for children and adolescents with severe mental health problems including psychosis, depression, suicidal ideation and intent and complex and coexisting disorders. The number of admission episodes in the year in which this study was undertaken exceeded 500, with an average length of stay of 5 days. Individuals with severe disorders such as psychosis and major depression experience a length of stay beyond the average, whilst those admitted in crisis are more likely to experience a length of stay below the average. The philosophy of care for all public inpatient and community-based services is to provide care in the least restrictive environment. The inpatient unit facilitates transition back to the community where it is anticipated that the long-term therapy, if required, will occur.

**Method**

Semi-structured interviews following the guidelines of Braun and Clarke (2013) were used in this qualitative study. Approval was sought and received from the appropriate hospital-based Human Research Ethics Committee (approval number: 2511/10/2015).

**Recruitment**

Participants were recruited from the list of carers accompanying young people admitted to one inpatient unit. At the time of admission, the admitting nurse informed both the young person and the carer about the study. Only carers of young people with whom the first author and interviewer, who was the clinical psychologist in the inpatient unit, had no professional or working relationship with were approached for participation. Additional information was offered about the nature of the study and those who had confirmed interest in participating were offered an appointment time to conduct the interview. Non-English-speaking carers were excluded from the study as were carers of children with a length of stay of 24 hours or less, due to time constraints regarding arranging and conducting interviews. All carers approached meeting the inclusion criteria agreed to participate in the study.
Procedure

Consent and confidentiality

Potential participants were provided with standardised information sheets prior to being asked to give their written consent for participation in the study. Written consent was obtained on the day of the interview (day of discharge). Confidentiality, privacy and anonymity were assured for all participants. Audiotaped interviews were transcribed with only de-identifying information provided. Once transcribed and following final analysis, the audiotaped interviews were erased.

Participants

There were 11 participants: 9 women and 2 men. Ten participants were biological parents of a young person admitted to the inpatient unit. One of the 11 participants was the maternal grandmother and legal custodian of the young person in her care. The diagnoses of children of carers admitted during the time of the investigation included adjustment disorder, suicidal ideation/self-harm, depression, psychosis (schizophrenia), mania and delusional disorder. Length of stay ranged from 2 to 35 days. Two of the children were admitted under an Involuntary Treatment Order.

Data collection

Interviews

Interviews were conducted between December 2014 and June 2015 in an office off the ward at the hospital in which the carer’s child had been hospitalised. Open-ended semi-structured interviews ranging from 28 to 55 minutes were conducted and audiotaped with participant consent, before transcription by the interviewer.

Each interview commenced with the broad question ‘Can you tell me about your experiences about accessing mental health services for your child?’ Additional interview questions were guided by the interviewees’ responses and were also complemented by previous participants’ responses. An audit trail was maintained during data collection and data analysis. The audit trail guides the decision to end sampling when data saturation is reached, that is the point at which collected data become repetitive and are not providing new information (Morse, 1995).

Data analysis

Thematic analysis following the guidelines of Braun and Clarke (2006, 2013) was applied to the interview data. This method involves six stages of analysis including: (1) data familiarisation, (2) code generation, (3) theme search, (4) theme review, (5) theme definition and naming and (6) report preparation. Emerging themes were initially identified and defined by the first author and subsequently redefined by all authors, until the main themes were established. Methodological rigour and trustworthiness (Tracy, 2010) were enhanced by the checking of the themes by both the second and third authors. Participant validation of the transcripts was attempted,
with one respondent making grammatical changes to the text in order to improve readability. The other respondents made no changes.

**Results**

The research question that guided this study was: are mental health services provided by community mental health services in the state in Australia in which this study was undertaken meeting the needs of carers of young people?

Three overarching themes emerged: experiences prior to admission, expectations about admission and the inpatient experience.

**Experiences prior to admission**

Participants described scenarios where they felt frustrated, annoyed and disappointed with the perceived inconsistency in availability and perceived quality of care offered by non-hospital-based services in particular. Many also expressed a belief that the inconsistency in care was potentially detrimental to the overall mental health of their child. The sub-themes representing these perceptions include: accessibility, service quality and barriers to admission.

**Accessibility**

There was a perception that community-based services for young people were difficult to locate and to access.

> I think there should be more supports in the public that should be listed so you can find it easily, it should be up there for everybody to see and readily available to people, not being so hard to find. (grandmother of child with suicidal ideation)

This lack of accessibility was particularly problematic for carers of young people living in rural and remote locations. A sense of helplessness about coping with their child in the absence of mental health support was often expressed.

> You go and see the mental health people at (nearest big country town). Then you got to wait at least another three or four days for someone else, a mental health specialist, to come down and see them, so you go to travel again, and in the meantime, what are you supposed to do about managing?. (mother of daughter with depression)

**Service quality**

Participants whose children had received community-based mental health services reported mixed experiences about the perceived quality of care. The concerns included: frequency of appointments; insufficiency of treatment and exclusion from therapy sessions.

**Frequency of appointments:** Frequency of appointments was perceived by participants as inadequate for in-depth assessment and diagnosis.

> In the community they only see her maybe tops twice a week and so it’s a bit hard. We explain what she’s like but it’s a bit harder if you don’t see it. You know it was hard before she came to hospital because no-one could work it out.
Furthermore, the infrequency of appointments was perceived as providing limited support to carers who were solely responsible for the wellbeing and management of their child from one appointment to the next. ‘So for 8 months nearly, we had a hard time at home’ (mother of daughter with mania).

*Exclusion from therapy sessions:* Participants although acknowledging the need for their child to speak privately with therapists, expressed a desire to be included in therapy sessions and dissatisfaction when this did not occur. ‘I felt very angry and hurt until we saw (therapist) and she said, no you can come in on the meetings’ (mother of son with suicidal ideation/self-harm). The exclusion from therapy sessions by carers was perceived as lack of recognition of the role they play in managing and maintaining the mental health of their child.

The perceived insufficiency and inconsistency of care offered and the desire for ‘more’ for their child contributed to carer perceptions that their child’s needs might best be met through inpatient care. However, participants also reported experiences about difficulties in achieving admission.

**Barriers to admission**

This sub-theme concerns carer perceptions of accessibility to inpatient mental health facilities. When the carer or referring parties believed that hospitalisation was the required treatment choice, frustration was expressed when further assessment did not result in hospitalisation.

they said that she desperately needs help, she sees a figure following her around all the time telling her to do things, so he said that she needed help, but we went to the (general medicine) hospital first, then we were referred to the children’s hospital and they questioned her and then sent her home. (mother of daughter with depression)

Participants reported that the difficulty in accessing services resulted in a further decline in their child’s mental health.

**Expectations about admission**

**Assessment**

Participants viewed the hospital admission as an opportunity to provide an in-depth assessment based on 24-hour care and observation. ‘Well in the hospital the nurse can keep an eye on her for 24 hours. That makes a big difference I suppose. They can judge her personality and how it changes’ (mother (1) of daughter with mania). This was a process that participants perceived as not being able to be achieved through outpatient appointments.

The second opinion by a mental health professional provided through such an assessment process was perceived as highly desirable in order to facilitate appropriate treatment, both during the admission as well as post discharge.

somebody else would have seen her, that can back it up and that can tell the people that we’ve gone to see, like at [mental health service], what their opinion is, and what needs to be done, what help she needs to keep getting so that she doesn’t hurt herself. (grandmother of child with suicidal ideation)
Inpatient experiences

Participants in this study overwhelmingly expressed the belief that the admission of their child to the inpatient unit was warranted and that it was a better alternative to community-based care.

I think we have a better understanding of what’s been happening for (son). It has gotten us more help, more regular help. I’m glad he’s here because I can see he can do it, he can go to school, he can go to the gym. (mother of son with suicidal ideation and self-harm)

Desire for a thorough assessment, understanding of the existing problem, treatment and hope of possibility of recovery for their child were perceived as having occurred as a consequence of the inpatient admission.

Relationship with staff

Availability of multidisciplinary inpatient staff who carers could communicate with throughout the day about concerns and decision-making was viewed in positive and satisfactory terms.

They always tell me in the morning how his night has been when I ring up, they tell me what the plan is for the day and they always ask me if I have any questions. They call me in for meetings we’ve had about three already and they make sure it is at a time I can make, so that’s all good too. Everyone’s been good. (mother of son with psychosis)

Ongoing concerns

Although acknowledging a greater sense of satisfaction and security of the care of their child during the inpatient admission, concerns resurfaced at the point of discharge. Those most concerned often linked the perceived inadequate duration of care as a factor. The sub-theme Ongoing concerns is supported by additional sub-themes: Length of stay, Relapse, Safety and Desired changes.

Length of stay: Participants were universal in their disappointment with the length of stay experienced by their child. ‘Well a week’s not long enough to get better or actually help him stay better’ (mother of son with suicidal ideation/self-harm). Participants were consistent in their reported fear of improvements gained during the inpatient admission not being maintained post discharge.

Relapse: Participants who were unhappy with the length of stay were also more likely to express concerns of their child relapsing: ‘I’d be really upset if he goes backwards, I want him better, I’m hoping that he is going to be fine in the community’. Reassurance and guarantee from hospital staff that their child would progress post discharge was also sought. ‘I want the hospital to tell me that he’s going to be fine and back to his normal self’ (mother of son with suicidal ideation/self-harm).

Safety: Despite acknowledging the education and support provided by the inpatient unit, many participants identified their own sense of inadequacy regarding knowing how to keep their child safe once discharged.

They’ve explained everything to us, but no offense, we have heard it all before, we understand why she might be doing what she is doing but none of that takes the feelings away, none of that makes us feel safe. (mother daughter with suicidal ideation)
**Desired changes**

Participants discussed changes to the inpatient experience that they perceived as beneficial to both their child and themselves as carers. Changes focussed on service type and delivery, as well as environmental factors.

In addition to the desire for a longer length of stay, participants expressed the desire for children to be accommodated according to their perceived degree of ‘wellness’. For example, young people requiring greater input from the inpatient unit in terms of assessment, treatment and support were accommodated in a ‘higher dependency section’. ‘Maybe a separate section for the really, really unwell kids who first come in’, whilst young people requiring less intense intervention were accommodated in a different section of the ward ‘and then another section for those that are getting better’. (Mother of son with psychosis).

**Continuity in care:** Participants acknowledged that having a known therapist with whom their child has established rapport would be perceived as more beneficial in the long term for their child. ‘Actually since she’s already been here why can’t she see the same person as an outpatient that would be better than having to start all over again with someone who really doesn’t know her’ (mother of daughter with adjustment disorder). Participants expressed a preference for their child to receive outpatient care from inpatient staff. In the absence of this possibility, participants expressed a desire for the mental health specialist providing care post discharge to their child to attend meetings and be active in post-discharge planning, whilst their child was still an inpatient.

Maybe if the person she is supposed to see in the community team could have seen her here while she was on the ward so she could already know what’s happening before, then that would be better. (mother of daughter with adjustment disorder)

**Discussion**

This study attempted to explore the experiences of carers during the process of accessing mental health services for their child. Participants viewed the perceived lack of appropriate and accessible community-based mental health services as not meeting their or their child’s mental health needs. By identifying factors carers found lacking, and identifying aspects carers felt would assist them in the care and management of their child’s mental illness, implications regarding service design and delivery are made.

Contrary to previous research (Geraghty et al., 2011), participants in this study reported greater dissatisfaction with community-based settings rather than the inpatient unit. The difficulty in accessing community-based mental health services, the perceived infrequency of appointments and inconsistency in treatment offered, as well as at times poor rapport with treating therapists were perceived by participants as contributing to a decline in the mental health of their child. People living in rural and remote areas of the state were particularly dissatisfied with accessibility, having to travel additional kilometres in order to access services and having to wait even longer times than their metropolitan counterparts, for specialist mental health assistance. Participants voiced dissatisfaction, fear and distress in having to carry the burden of responsibility for the safety and wellbeing of their child whilst attempting to seek out appropriate care.

Factors identified in previous research as important to carers of young people suffering from mental illness such as a comprehensive assessment of their child, inclusion in
decision-making about their child’s care, positive interactions with staff, education about their child’s illness and liaising with other services on behalf of the child and their carer (Brinkmeyer et al., 2004; Crow et al., 2002; Gavidia-Payne et al., 2003; Gerson et al., 2009; Pinfold et al., 2004) were also perceived as satisfactory aspects of the inpatient care by participants of this study.

Disappointment with community-based services appeared to result in carers continuing to actively seek hospitalisation for their child in the hope that the inpatient unit could provide the support they perceived lacking in the community. This was the case even when attempts at having their child hospitalised failed previously. It also influenced the desire of carers to seek out longer lengths of stay for their child fearing treatment in the community would not be sufficient to maintain any improvements made from the inpatient stay. Participants perceived inpatient care as not only the most appropriate for their child, but as providing them with a sense of relief at not having to assume complete and sole responsibility for the management of their child’s illness and safety.

This preference for hospital-based services is in contradiction to the desired evolution of care from hospital to community-based care. It is not necessarily unexpected. The preference for hospital-based care can be explained with the concept of containment. Containment is an aspect of inpatient care children and adolescents themselves have identified in previous studies (Gilbert, Rose, & Slade, 2008; Haynes, Eivors, & CROSSLEY, 2011; Hepper, Weaver, & Rose, 2005) as a positive aspect of the inpatient experience. An inpatient unit provides both physical containment of the individual and emotional containment for the carer who is often experiencing fear about maintaining their child’s safety. The fact that the child has been hospitalised instils in the carer the perception that the treatment offered is intensive, continuous and productive. Community-based care as described by participants in this study is often sessional and inconsistent and at times also perceived as exclusive of carer involvement.

Participants in this study viewed inclusion in the treatment of their child as highly important. Community-based teams that were perceived as not actively encouraging inclusion of carers in therapeutic sessions with their child resulted in anger and frustration on the part of the carer. However, advances in mental health has meant greater acknowledgment of the consumer in decisions about their care. This includes enabling young people to have a voice and be heard. Young people 16 years and over in the Australian state in which this study was undertaken are able to give informed consent about their treatment options. This includes honouring the request to not involve their carers in the provision of services offered. In order to respect the wishes of young people (Ward-Griffon, Schofield, Vos, & Coatsworth-Puspokey, 2005) and maintain rapport which in turn might influence continuity in care (Rey et al., 1999; Scharer, 2000), choosing not to include carers is not a decision that is taken lightly.

In the inpatient unit where the end result of the time limited care is often ‘discharge home to the carer’, emphasis on attempting to include carers in treatment and discharge plans is mandatory, unless specifically requested otherwise by the child. Even then, explanation of reasons for non-inclusion is offered to the carer and compromise between child and carer is attempted. This is of particular importance with children who present with chronic self-harm and suicidal attempts. Carers are often in a heightened state of distress about maintaining safety for their child and must be included in management plans. If inclusion in therapy with their child is not feasible, then providing additional support
for carers, such as individual appointments for them on a more regular basis, is an alternative. Although this is a process that often does occur in community-based teams, participants in this study perceived the frequency to be insufficient.

As participants viewed the inpatient unit as ‘the right place’ for their child, the prospect of discharge triggered fear and uncertainty, particularly for carers of children with suicidal and self-harm behaviours. Children and adolescents transitioning back to the community have in previous research also identified the point of discharge as a time of concern (Gill et al., 2016). Although participants acknowledged greater understanding of their child’s illness as a consequence of the admission process, that did not alleviate any of their concerns about responsibility for ensuring their child did not relapse once discharged. This concern highlights the need for additional support for families that can act as a buffer between inpatient and outpatient care for young people deemed at high risk.

Mental health service delivery pathways in the state in which this study was conducted are designed for post-discharge follow-up to occur outside of and separate from the inpatient unit. However, carers in this study continued to favour contact with inpatient services and staff post discharge of their child. This is a novel result. The suggestions offered by carers included a separate step down unit that caters for long-term admissions and specifically for young people at risk. In absence of this, carers suggested more active participation in the admission episode by the community-based mental health team who would be responsible for care of their child post discharge. Although this is a process that is already encouraged in the state in which the study occurred, in reality it has proven difficult to achieve. Community-based mental health clinicians often operate on a fixed appointment diary basis and availability to attend hospital-based sessions is not easily achievable without sufficient notice. The length of stay, which is often around 5 days, contributes to this problem. Creativity of service delivery is required and the use of telehealth facilities, face-time, phone link-up or after-hour consultations may warrant further investigation.

The results of this study support the existing literature that states carers’ desires for education about their child’s illness, inclusion in the management and decisions about care of their child and respect for their knowledge and expertise regarding their child’s mental health issues are of great relevance in influencing satisfaction with mental health services. This study has also highlighted that when these desires and expectations are not met, then dissatisfaction and reluctance to return to the service deemed ‘lacking’, in this case, community-based mental health services, is likely to occur.

This study has identified the specific reasons for why hospitalisation is desired as the most appropriate form of intervention for young people when most previous research identifies it as the source where most dissatisfaction occurs (Geraghty et al., 2011). Safety, risk and the anxiety about managing these aspects of their child’s mental illness were repeatedly identified by carers as a source of concern that can, only for those participants in this study at least, be contained by a secure inpatient unit. The intensity and frequency of assessment and review are further reasons for the preference for inpatient as opposed to community-based care.

When concerns about service type, availability and accessibility are repeatedly raised, changes to accommodate concerns must be considered and, where appropriate, made. Participants in this study have clearly articulated their concerns about maintaining their child’s safety and request additional community-based services or changes to service
delivery that can ‘share the responsibility’ and lift the burden of care. Providing care in the least restrictive environment can only be a successful evolution if appropriate supports are available to those individuals responsible for providing that care.

This study adds to the very limited body of research about the referral and admission process of young people suffering from mental illness from the perspective of their carer. Furthermore, it sets the path for research that aims to identify appropriate support and resources required to assist carers in managing the mental health of their children. This is particularly important from the background of policy that aims to provide care for young people experiencing mental health problems in the least restrictive environment.

A relative weakness of this study is that the findings may be relevant only to the state in which this study was conducted, as comparisons with other mental health services elsewhere were not attempted. Furthermore, only parents/carers with children admitted to the inpatient unit were included in this study, therefore potentially influencing their preference for hospital over community-based care. The exclusion criteria for participants in this study resulted in categories of participants for whom we have no information about the inpatient experiences of their child. Information is lacking on the perceptions and experiences of carers of young people who did not accompany their child to the inpatient unit at admission, or from carers whose child’s inpatient experience was of a duration of 24 hours or less. The exclusion of non-English-speaking carers has also resulted in a lack of perspective from culturally and linguistically diverse individuals. However, the process of evaluating a mental health service from the perspective of any consumer group is one that can be applied universally.

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