

**The transition from adolescent inpatient care back to the community: Young
people's perspectives**

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

Whilst the majority of adolescents receive support from mental health services in community settings, some have problems that reach a level of severity and complexity that requires admission to hospital. Little is known, however, about how the young person adjusts and reintegrates back home following discharge from an inpatient unit.

Part 1 is a literature review evaluating the evidence-base of alternative provisions to inpatient care for children and young people with severe and complex mental health problems. A total of 13 studies were identified for inclusion, and five intervention types were classified. The majority of the studies reported positive outcomes, but the strength of their designs varied. Overall, the studies provided promising findings for the effectiveness of community-based interventions for children and adolescents with complex mental health needs.

Part 2 is a qualitative study that explored adolescent inpatients' anticipations about the transition from inpatient care back into the community, that was informed by Self Determination Theory (Deci & Ryan, 1980). Semi-structured interviews were conducted with 12 adolescent inpatients and transcripts were analysed using thematic analysis. The adolescents saw the transition back home as providing both opportunities (e.g. personal growth) and challenges (e.g. re-entering the "real world" and negative perceptions from others).

Part 3 is a reflective discussion of the process of developing and carrying out the qualitative study. It focuses on three areas: issues of self-reflexivity, the process of interviewing adolescents, and the tensions of balancing a phenomenological approach whilst being informed by a theoretical framework.

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Part 1: Literature Review

Alternatives to inpatient care for children and adolescents with severe and complex mental health problems

Abstract

Aims: To date there is limited research evaluating service provisions for children and adolescents with severe and complex mental health problems. This review aimed to critically evaluate the evidence-base of alternative provisions to inpatient care for children and young people and provide a summary of the interventions reported in the current literature.

Method: Studies were identified through a systematic search of the online databases PsycInfo, MEDLINE and Embase. The studies included in the review were rated for quality using an adapted version of a checklist developed by Downs and Black (1998).

Results: A total of 13 studies were included in the review. Interventions were classified into five types based on the nature of the delivery: multi-systemic therapy, assertive community treatment, intensive day treatment, wraparound services and family preservation services. Overall findings revealed significant improvements in participants' psychological functioning and behaviour, and significant reductions in out-of-home placements. A multidisciplinary and multiagency approach was a common feature of the interventions. Variation was found between the quality of the studies in terms of design features and methodological rigour.

Conclusions: Overall, the studies under review provide promising findings for the effectiveness of community-based interventions for children and adolescents with complex mental health needs. There remains, however, limited evidence in terms of 'what works for whom' and scope to offer guidance for the further development of services. Further research is needed to assess for longer-term outcomes and whether positive changes are maintained, and to establish the cost-effectiveness of the interventions available.

Introduction

Children and adolescents with the most severe and complex mental health problems are typically supported within Tier 4 child and adolescent mental health services (CAMHS) in the UK. These services form part of a highly specialised pathway that is tailored for a level of complexity that cannot be provided by comprehensive secondary (Tier 3) services. The National Service Framework (NSF) for Children, Young People and Maternity Services by the Department of Health (DH) set the standard that all young people requiring Tier 4 CAMHS should have access to a range of services including intensive outpatient services, assertive outreach, inpatient residential and other highly specialised services in order to meet the needs of children and young people with complex needs (DH, 2004b). The term ‘young people’ is used interchangeably with ‘adolescents’ within this thesis, and refers to individuals aged between 12 and 18 years old.

There is strong evidence that inpatient services are effective for children and young people with severe mental health problems (Blantz & Schmidt, 2000; Green et al., 2007; Pfeiffer & Strzelecki, 1990). There is an ongoing debate, however, about the advantages and disadvantages of inpatient care. Key disadvantages include high care costs, the loss of support from the young person’s local community, institutionalisation effects, disruption in educational attainment, and the detrimental impact on families when a young family member is removed from their home setting (e.g. Green & Jones, 1998; Sharfstein, 1985). The possibility of providing intensive psychiatric and psychosocial interventions without removing the patient from their natural environment is therefore of particular importance for young people with psychiatric disorders (e.g. Petti, 2010) and has led to a move towards alternatives to the traditional inpatient

treatment and the development of new models of intensive home and community-based care (e.g. Darwish, Salmon, Ahuja & Steed, 2006; Henggeler et al., 1997; Van Den Berg & Grealish, 1996).

There is a growing body of research evidence supporting the use of alternatives to inpatient admission for certain groups of children and young people with mental health problems (Ahmed, Salmon, Ahuja & Steed, 2006; Woolston, 1998). An ‘alternative to inpatient care’ has been defined as a service for young people with serious mental health problems who are at high risk of being admitted to an inpatient unit (Department of Health, 2004b). McDougall and colleagues provide a comprehensive overview of the Tier 4 services currently available for children and young people whose needs require highly specialised interventions (McDougall, Worrall-Davies, Hewson, Richardson & Cotgrove, 2008). In their paper they identify the key components of these intensive community services: home-based treatments with small caseloads, individually tailored packages of care and the prevention of family breakdown. Compared with the literature on adult populations, however, research assessing the effectiveness of alternative Tier 4 services for children and young people remains limited (Lamb, 2009). This is of particular concern given the increasing financial pressure on both public and private health services to demonstrate the effectiveness of service provision through evaluation studies. The existing research has been criticised for lacking precise details regarding the interventions’ duration and intensity, as well as the training and qualifications required to conduct such an activity (Shepperd et al., 2008).

To date only a handful of reviews evaluating the effectiveness of these alternative care provisions have been published. The first highly stringent systematic review was produced by Shepperd and colleagues in 2008 as part of a report for the National

Institute for Health Research (Shepperd et al., 2008). The report includes analysis of the effectiveness of the different models identified, in addition to a mapping study of services in England and Wales. Through a comprehensive search strategy the authors identified 17 comparison studies (in addition to 41 descriptive studies) that described eight distinct models of care: multi-systemic therapy (MST), day hospital, case management, specialist outpatient services, home treatment, family preservation services, therapeutic foster care, and residential care. Findings were mixed, with an uneven spread of research evidence; for example randomised controlled trial (RCT) data was only available for four out of the eight treatment models (MST, specialist outpatient services, home treatment, and family preservation services). MST yielded the most robust evidence, with improvements in functioning reported at discharge. These findings, however, were not sustained at four months follow-up indicating poor maintenance of treatment effects. The weakest evidence came from therapeutic foster care and residential care where only a single descriptive (uncontrolled pre-post-test) study was found for each treatment model. The overall findings of this large scale review highlighted the paucity of research available, and the need for more evaluations to be conducted.

The following year Shepperd and colleagues published a Cochrane systematic review restricted to randomised controlled trials (RCTs), the gold standard for treatment efficacy (Shepperd et al., 2009). The same RCT data from their government report was reviewed (Shepperd et al., 2008) (i.e. seven RCTs comparing alternative treatments to inpatient care for children and young people). This highlighted the scarcity of good quality research that was available in the literature at the time, offering little guidance for the development of services. Several limitations, however, should be noted with

Shepperd et al.'s reviews (Shepperd et al., 2008; Shepperd et al., 2009). Highly stringent inclusion criteria were used, with a key criterion being studies where treatments were directly compared to inpatient care or an equivalent alternative. This is likely to have substantially reduced the potential for identifying the range of services available and prevented the identification of good quality practice-based evidence that does not involve comparison groups. It could be argued that the complex nature of the client group, in terms of problem severity and systemic influences, makes it difficult to develop good quality RCTs, which require a level of control and equivalent comparison that cannot be easily achieved for such a population and or treatment modality. This may be one reason for the limited number of RCTs and it highlights the need for other research designs to be considered in understanding the effectiveness of services for children and young people.

In light of this, the current review aimed to broaden the type of research designs to include all studies with clearly defined pre- and post-treatment outcomes (e.g. quasi-experimental designs, uncontrolled trials). It was anticipated that this would expand the available study set and offer examples of practice-based evidence as well as efficacy trials. Given the recent push from the government to increase the evidence-base in order to inform the development of specialised services for children and young people with the most complex and severe mental health problems, it is important to consider new studies available since Shepperd et al.'s (2008, 2009) reviews. The current review therefore aimed to examine recent developments in the evidence for alternatives to inpatient care, and evaluate the quality of the current research available.

Aims of the current review

In summary, the current review aimed to broaden and update Shepperd et al's (2009) review in order to address the following objectives:

1. To identify the effectiveness of alternative to inpatient models of care for children and young people with severe and complex mental health problems.
2. To critically appraise the methodological quality of the studies and identify important gaps and areas for further research.

Method

Inclusion criteria

Studies were included if they met criteria in four key areas:

1. Types of interventions

The interventions under study were mental health services providing specialist care, beyond the capacity of generic outpatient provision, for children and adolescents with severe mental health problems. This included services for 'hard to reach' patients who would not engage in generic outpatient services. Services that were not described as primarily targeting severe mental health or emotional/behavioural problems (e.g. where mental health was a secondary target) were excluded.

2. Participants

The study population was children or adolescents, aged five to 18 years, with a serious and/or complex mental health problem. This included individuals described as suffering from non-specific psychiatric, emotional or behavioural

disorders. Studies were included if the mean age of the participants fell within the 5-18 years age range, even if some participants fell outside of this range. Children and adolescents described as having a primary diagnosis of a developmental or intellectual disability, mild mental health disorders, a primary problem of juvenile delinquency and those receiving care for physical illnesses were excluded.

3. *Study design*

Studies were included if they had clearly defined pre- and post-outcome measurement (e.g. RCTs, quasi-experimental designs or uncontrolled trials). Descriptive studies were excluded.

4. *Outcome measures*

Studies were required to measure outcomes in terms of disorder-specific symptoms or general psychological functioning. Other outcomes included admission rates to inpatient care and length of stay, use of out-of-home placement and school functioning.

Search methods for identification of studies

The electronic databases PsycINFO, MEDLINE and Embase were initially searched on 18th September 2014 and then re-run for the final search on 15th January 2014 through the OVID search engine. These were selected based on Shepperd et al.'s (2009) review. Each database was searched individually, to allow for search terms to be amended accordingly. Additional papers were also searched for by examining the reference lists of retrieved studies and publication citations.

Search terms were selected based on examining the papers reviewed in Shepperd et al.'s (2009) review and other existing literature (e.g. McDougall et al., 2008), from which key words from the titles and abstracts were identified. The search terms were broken down into three core concepts using the PICO tool: population, intervention, and study design. The final search incorporated a combination of the following keywords: *(adolescen* OR child* OR youth*) AND (mental health OR psychiatric disorder* OR emotional disorder* OR behavior* disorder*) AND (intensive OR assertive OR crisis resolution OR specialist OR home treatment OR outreach OR alternative OR multisystemic therap* OR multi-systemic therap* OR day hospital* OR case management OR family preservation service* OR therapeutic foster care OR residential) AND (longitud* OR compari* OR clinical trial* OR randomi* OR evaluat* OR effective* OR effica* OR outcome* OR experiment*)*.

Search terms were limited to 'title' and 'abstract' search fields in order to ensure only relevant papers were retrieved. Only studies published in peer-reviewed journals and written in English were included. As the main aim of the current review was to update Shepperd et al.'s (2008, 2009) review, the publication date was set to 2007 onwards. As Shepperd et al. (2008, 2009) had included only two papers published in 2007 (Byford et al., 2007; Gowers et al., 2007) these were excluded from the current review.

Study selection

Figure 1 shows the process of identifying and selecting studies. Results from the three databases were combined and duplicates removed, identifying a total of 1038 papers. As a preliminary step, the titles of all papers were screened, and studies

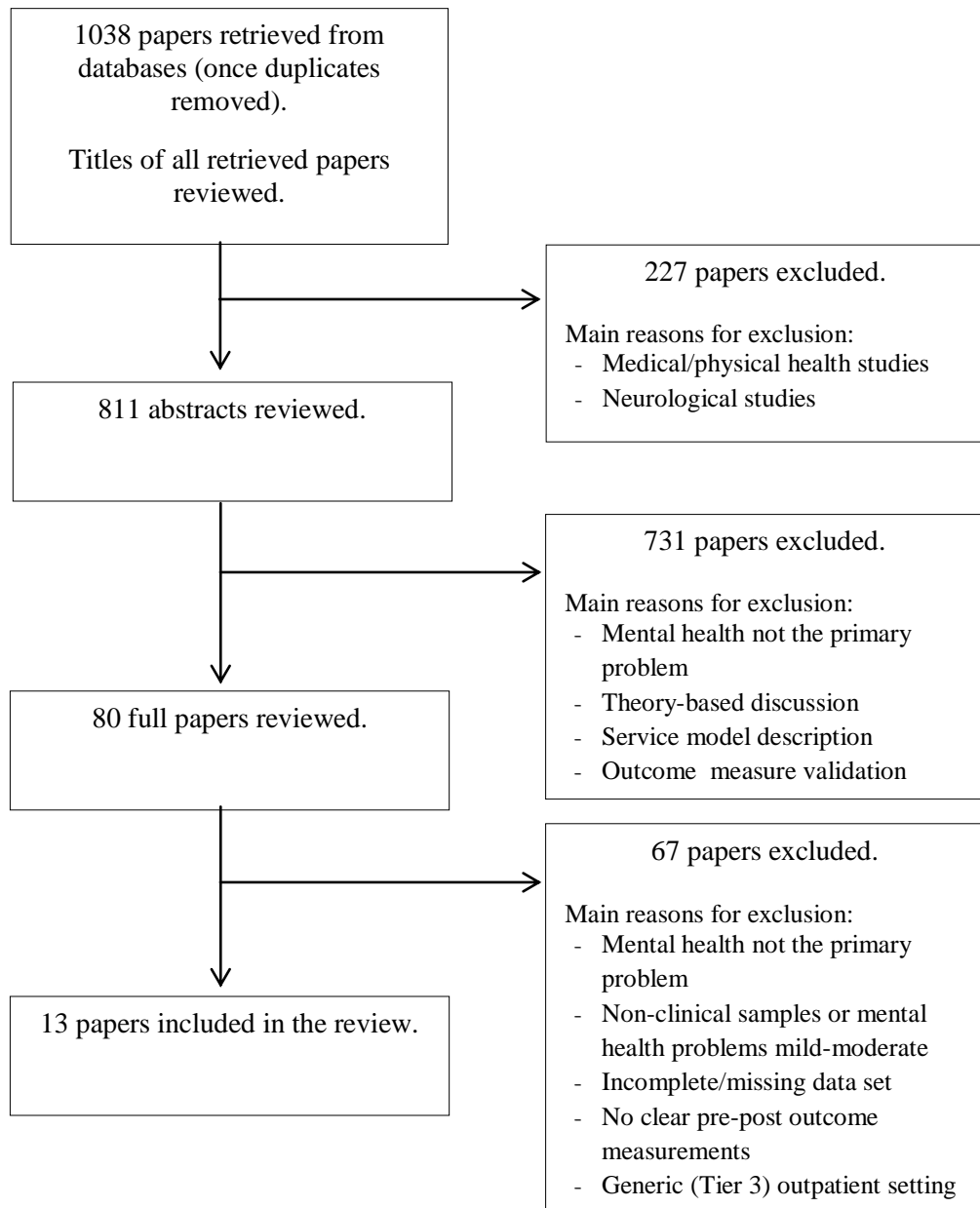
considered irrelevant based on their title were excluded (e.g. medical studies). The abstracts of all the remaining papers were read to identify potentially eligible studies. The main reasons for exclusion at this stage included the absence of a primary mental health problem, theory-based papers or service model descriptions. From this 80 papers were retrieved, read in full, and compared to the inclusion and exclusion criteria. Papers were typically excluded at this stage because of participant characteristics (e.g. mild mental health problems or the primary problem being juvenile delinquency) or design characteristics (e.g. no clear pre-post measures). A total of 13 papers met the inclusion criteria and formed the study set for the current review.

Quality assessment

Studies were appraised using a modified version of Downs and Black's (1998) quality checklist (Cahill, Barkham & Stiles, 2010). Cahill et al. (2010) adapted the original checklist in order to make it more relevant for evaluating practice-based evidence. The checklist was chosen for this review as it is suitable for small-scale quasi-experimental or uncontrolled studies as well as large-scale efficacy trials.

The checklist contains 32 items assessing a range of quality criteria (see Appendix A). Studies are scored depending on whether they meet the criteria associated with each item on the checklist. A study receives a score of one if it meets the criterion or a score of zero if it does not (or if it is not possible to determine). Based on the scores, four quality indices can be computed: (1) reporting; (2) external validity; (3) internal reliability; (4) internal validity-confounding (selection bias). The checklist also yields an overall quality score out of 32.

Figure 1: Flow chart of search and selection process



Results

Across the 13 studies, five different types of intervention were evaluated (see Table 1). Table 2 presents details of the 13 studies under review, categorised by intervention type. Table 3 shows scores for each study on the four quality domains of the Cahill et al. (2010) checklist, in addition to the means and ranges across the study set. The quality of the studies is considered first, followed by a synthesis of the findings (short- and long-term outcomes) for each intervention type.

Table 1: Intervention categories

Intervention type	Number of studies
Assertive community treatment	5
Wraparound services	3
Multi-Systemic Therapy (MST)	2
Intensive day treatment	2
Family preservation services	1

Table 2: Description of individual studies

Author (date)	Intervention	Sample	Design and assessment points	Outcome variables	Results
Assertive community treatment					
Baier et al. (2013)	AIMA - Antenne d'Intervention dans le Milieu pour Adolescents (Mobile team for adolescents).	35 young people (13-18 years) with mental health problems who refused outpatient treatment.	Uncontrolled trial. Baseline and discharge assessments.	HoNOSCA	Significant improvement in mental health and functioning post-treatment.
Chia et al. (2013)	Adolescent Intensive Management (AIM) Team.	64 young people (11-17 years) with range of mental health problems, assessed as being high risk referred to the service. 59 cases with full data analysed.	Uncontrolled trial (retrospective evaluation). Baseline and discharge assessments.	CGAS; Psychiatric hospital usage; Engagement in education/vocation	Significant decrease in readmissions to hospital during intervention. Improved school attendance post-treatment (full-time attendance: 23% to 56%). Significant improvement in overall functioning post-treatment ($p < .001$).
Duffy & Skeldon (2014)	CAMHS Intensive Treatment Service (ITS)	113 young people (7-17 years) with range of mental health problems including mood disorders and self-harming behaviours. 71 complete data sets.	Uncontrolled trial. Baseline and discharge assessments.	CGAS; HoNOSCA; WHOQOL-BREF; BYI-II; PCS	Statistical and clinically significant changes in overall functioning and mood ratings post-treatment.
Schley et al. (2012)	Intensive Mobile Youth Outreach Service (IMYOS).	44 young people (14-25 years) with severe mental health problems referred to the service.	Uncontrolled trial (retrospective evaluation). Baseline and discharge assessments.	BPRS; HoNOSCA; GAF; Measure of engagement	Significant improvement in wellbeing and functioning, and reduction in suicidality and hostility. Positive correlation between engagement and 'favourable' hostility outcome at discharge, and greater wellbeing and functioning.

Table 2 Continued

Author (date)	Intervention	Sample	Design and assessment points	Outcome variables	Results
Assertive community treatment (cont.)					
Simpson et al. (2010)	Fife Intensive Therapy Team (FITT).	57 young people (11–17 years) deemed very high risk of admission to an inpatient hospital. 55 complete data sets were assessed.	Uncontrolled trial (retrospective evaluation). Baseline and discharge assessments.	HoNOSCA; Admission to inpatient unit	Significant improvement in overall functioning post-treatment and reduced inpatient admission during treatment (27 to 6). Positive correlations between change in HoNOSCA score and treatment duration ($r=0.363, p=.006$) and number of clinical contacts ($r=0.426, p=.021$).
Wraparound services					
Copp et al. (2007)	Wraparound service.	45 children (8–14 years) with severe behavioural and attentional problems enrolled in wraparound study. 15 children with complete data set were assessed.	Uncontrolled trial. Baseline and 6 months follow-up assessments.	CBCL; CAFAS	No significant differences found on any variable.
Painter (2012)	Wraparound service.	160 young people (5–17 years) with SED.	Uncontrolled trial. Baseline, 6 months, 12 months, 18 months and 24 months assessments.	BERS-2; CBCL; RADS-2; RCMAS-2; CIS; CGSQ; YSS; YSS-F	Significant reductions in behavioural problems, child anxiety, functional impairment and caregiver strain at 2 years follow-up.
Solbk et al. (2007)	Home and Community-Based Services (HCBS) Waiver Program.	169 young people (5–18 years) with serious emotional disturbance.	Non-randomised quasi-experimental design: all participants formed both the intervention group and waitlist control group. Baseline (waitlist) and discharge assessments.	Home placement stability; Rate of inpatient psychiatric hospitalization	81% were maintained in the community during treatment, compared to 31% when on waiting list for treatment.

Table 2 Continued

Author (date)	Intervention	Sample	Design and assessment points	Outcome variables	Results
Multi-Systemic Therapy (MST)					
Painter (2009)	MST	174 young people (13.6 years mean) with mental health externalising disorders (e.g. conduct disorder). Not involved in juvenile offender settings.	Non-randomised quasi-experimental design: intervention group (n=87) or TAU (n=87). Baseline and discharge assessments.	CA-TRAG	Significant treatment effects found for school behaviour, family functioning, mental health symptoms, youth functioning compared to TAU. No group differences in overall functioning
Stambaugh et al. (2007)	1) MST 2) Wraparound 3) MST + wraparound	320 young people (4-17.5 years) referred to the children's mental health service. Rates of attrition at follow-up: 11% (n=32) at 6 months; 28% (n=89) at 12 months; 37% (n=118) at 18 months.	Non-randomised quasi-experimental design: intervention group (n=54) compared to 2 comparison groups (wraparound (n=213) and wraparound+MST (n=53)). Assessment at baseline, 6 months, 12 months and 18 months.	CBCL; CAFAS; MSSC	Intervention group showed the most improvement in clinical symptoms at 18 months (including moving out of clinical range of impairment: 62% on CBCL; 66% minimal-moderate range on CAFAS).
Intensive day treatment					
Jerrott et al. (2010)	Child and Family Day Treatment program.	57 children (6-13 years) with a primary diagnosis of DBD.	Non-randomised quasi-experimental design: intervention group (n=40) compared to waitlist controls (n=17). Baseline and discharge assessments.	CBCL; CPRS-R:S; PSI; ECBI	Significantly improved outcomes across all measures in treatment group. Large effect sizes between treatment and waitlist groups at discharge on child aggressive, externalising and intensity of behaviours (d=.79 to 1.01).

Table 2 Continued

Author (date)	Intervention	Sample	Design and assessment points	Outcome variables	Results
Intensive day treatment cont.					
Thatte et al. (2013)	Partial hospitalization program.	140 young people (14-19 years) with a diagnosed psychiatric disorder referred to the programme. 55 completed the programme and were assessed.	Uncontrolled trial. Baseline, discharge and 3 months follow-up assessments.	BPRS-E; CGI; CAFAS; LSDS-B	Significant improvements in clinical symptoms and psychosocial functioning between baseline and discharge. No significant differences found between discharge and 3 months follow-up across all measures, however, scores from admission and follow-up remained significant.
Family preservation services					
Lee et al. (2009)	Integrated Family and Systems Treatment (I-FAST).	77 young people (4-17 years) at risk of out-of-home placements, and their families.	Uncontrolled trial (feasibility study). Baseline, discharge and 6 months follow-up assessments.	The Ohio Scale-Short Form; Child's placement status; FACES-II; PSE; FPM	Significant decrease in problem severity and increase in functioning at discharge. Non-significant changes at discharge to 6 months follow-up across measures, however, significant changes from pre-treatment to 6 months follow-up. Out-of-home placements significantly reduced post-treatment (5.1% compared to 40.7% pre-treatment). Improvements in family functioning across measures.

Note abbreviations of outcome measures: BERS-2 = Behavioral and Emotional Rating Scale; BPRS = Brief Psychiatric Rating Scale; BPRS-E = Brief Psychiatric Rating Scale -Expanded Version; BYI-II = Beck Youth Inventories-Second Edition; CAFAS = Child and Adolescent Functional Assessment Scale; CA-TRAG = Child and Adolescent - Texas Recommended Assessment Guidelines; CBCL = The Child Behavior Checklist; CGAS = Children's Global Assessment Scale; CGI = Clinical Global Impression; CGSQ = Caregiver Strain Questionnaire; CIS = Columbia Impairment Scale; CPRS-R:S = Conners' Parent Rating Scale Revised: Short Form; ECBI = Eyberg Child Behaviour Inventory; FACES-II = Family Adaptability and Cohesion Evaluation Scales; FPM = Family participation measure; GAF = Global Assessment of Functioning; HoNOSCA = Health of the Nation Outcome Scales for Children and Adolescents; LSDS-B = Life-Skills Development Scale-Adolescent Form; MSSC = The Multisector Service Contact Questionnaire; PCS = Paddington Complexity Scale; PSI = Parenting Stress Index; PSE = Parental Self-Efficacy Scale; RADS-2 = Reynolds Adolescent Depression Scale; RCMAS-2 = Revised Children's Manifest Anxiety Scale; WHOQOL-BREF = World Health Organisation Quality of Life Instrument (short version); YSS-F = Youth Services Survey for Families.

Table 3: Quality ratings of the studies

Study	Reporting (total = 11)	External validity (total = 11)	Internal reliability (total = 5)	Internal validity – confounding (total = 5)	TOTAL SCORE (total = 32)
Assertive community treatment					
Baier et al. (2013)	7	7	3	0	17
Chia et al. (2013)	4	8	3	1	16
Duffy & Skeldon (2014)	5	8	3	0	16
Schley et al. (2012)	8	8	3	0	19
Simpson et al. (2010)	8	7	3	1	19
Wraparound services					
Copp et al. (2007)	6	6	1	1	14
Painter (2012)	6	7	4	1	18
Solhkhah et al. (2007)	7	8	3	3	21
Multi-Systemic Therapy (MST)					
Painter (2009)	8	7	5	3	23
Stambaugh et al. (2007)	8	6	3	4	21
Intensive day treatment					
Jerrott et al. (2010)	7	5	3	3	18
Thatte et al. (2013)	8	8	3	2	21
Family preservation services					
Lee et al. (2009)	7	7	3	1	18
MEAN SCORE (RANGE)	6.8 (4-8)	7.1 (5-8)	3.1 (1-5)	1.5 (0-4)	18.5 (14-23)

Overall study quality

The quality of the studies in the review was mixed, with an average overall score of 18.5 out of 32.

Reporting

There was considerable spread amongst the studies in terms of the quality of reporting, with scores ranging from four to eight out of 11. Reporting of the distribution of principal confounders was poorly described, with no studies including adjustment regression or matching of participants. There was a mixed approach across the papers in providing an account of the intervention and professionals involved in the delivery, with several papers offering only a very brief description (e.g. Copp, Bordnick, Traylor & Thyer, 2007; Lee et al., 2009). A common weakness of the studies was the failure to provide full details of characteristics of participants lost to follow-up. Furthermore, very few studies included any measurement of clinical- as opposed to statistical- significance, making it difficult to ascertain the extent to which observed changes in outcome measures were meaningful for the participants who took part.

External validity

External validity, the extent to which the results of a study can be generalized to other situations and people, was rated the highest amongst the indices. This is explained by the majority of the studies being part of routine care, delivered by experienced professionals with regular caseloads. Another common strength across the studies was that the participants consisted of unselected samples of consecutive clients (e.g. all referrals over a two year period) which enhanced the clinical representativeness of the samples being assessed. Few studies, however, provided training in the specific treatment being studied (e.g. Solhkhah, Passman, Lavezzi,

Zoffness & Silva, 2007; Stambaugh et al., 2007) and only a handful of studies utilised treatment fidelity checks (e.g. Lee et al., 2009; Stambaugh et al., 2007).

Internal reliability

Internal reliability refers to the risk of bias in the delivery and measurement of interventions and their outcomes. Mixed ratings were given for this index, with a modal score of three out of five. A common strength of the studies was the predominant use of child and adolescent outcome measures that are not only routinely used within clinical settings, but also have established psychometric properties (e.g. CBCL, HoNOSCA). On the whole, most studies used appropriate statistical tests to evaluate the interventions; however, several studies' use of parametric tests could be questioned given the small sample sizes (e.g. Copp et al., 2007). Interestingly, the majority of the studies evaluating assertive outreach interventions relied solely on clinician-based outcome measures, which raises concerns about possible reporting bias and limits the breadth of feedback and variety of perspectives considered in the evaluation of the intervention.

Internal validity – confounding

The internal validity-confounding index relates to the risk of confounding factors and selection bias. This was the poorest rated index, with a mean score of 1.5 out of five. Studies were variable, which is likely to be reflective of the range of study designs included (e.g. quasi-experimental and uncontrolled studies). No RCTs were included in the study set, which significantly limited the quality of evidence reviewed in terms of internal validity. No studies conducted intent to treat analysis, and instead based their analysis on treatment-only data, which raises significant concerns about the reliability of the data and the conclusions that can be drawn. A key issue across studies was the lack of follow-up data. Only six studies conducted

follow-up analysis (Copp et al., 2007; Jerrott, Clark & Fearon, 2010; Lee et al., 2009; Painter, 2012; Stambaugh et al., 2007; Thatte, Makinen, Nguyen, Hill & Flament, 2013). The absence of follow-up evaluation of the remaining studies limited the conclusions that could be drawn about the longer-term effects of the interventions, and whether clinical change is maintained. Furthermore, a major limitation for nine out of the 13 studies was the lack of control or comparison group. The findings therefore need to be interpreted with caution, as the observed changes may be due to factors other than the intervention (e.g. maturation effects).

Assertive community treatment

Intervention characteristics

Assertive community treatment, sometimes known as intensive case management, is a specialist service for young people with mental health and behavioural problems that are deemed too severe to be managed at the generic level of practice. The targeted young people are often described as ‘high risk’ or ‘hard-to-engage’, at risk of psychiatric inpatient admission. The overarching aim of the treatment is to build and sustain therapeutic engagement with the young person and their carers, and maintain the young person in the community (Simpson, Cowie, Wilkinson, Lock & Monteith, 2010). Assertive community treatment adopts a flexible, collaborative outreach approach that is responsive to the changing needs of clients (Schley, Yuen, Fletcher & Radovini, 2012). Interventions are multifaceted and typically incorporate the individual, their family/carers and support system (e.g. education, social care). This can include a combination of individual therapy, crisis management, systemic therapy, supervision and debriefing, and collaboration and consultation with other agencies.

The coordination and responsibility of care for an individual child or young person is assigned to an individual practitioner. The allocated case manager offers clinical contact in the least restrictive environments, most commonly in the client's own home, at their school, or in public locations such as parks or cafes. Frequency and duration of contacts vary depending on the clinical need and complexity of presentation, although this is often several times per week on average. In order for this to occur, caseloads tend to be low (e.g. <6 per clinician; Simpson et al., 2010). Variations were found amongst the studies in relation to the professionals who delivered the treatment (e.g. predominantly nurse-led in Simpson et al., 2010); however, all used a multi-disciplinary approach.

Treatment outcomes

Intensive case management was evaluated by five one-group uncontrolled trials (Baier, Favrod, Ferrari, Koch & Holzer, 2013; Chia et al., 2013; Duffy & Skeldon, 2014; Schley et al., 2012; Simpson et al., 2010), each of which reported positive findings. Baier et al., (2013) found significant improvements and large effect sizes ($d=1.27$) in the mental health and overall functioning of young people receiving an assertive community treatment. In terms of design quality, Baier et al. (2013) conducted a substantial amount of statistical testing (e.g. t -tests for each item of HoNOSCA) which appeared excessive and inappropriate, although their use of Bonferroni correction helped to reduce the risk of making a type 1 error. Furthermore, although the HoNOSCA has good inter-rater reliability and face validity (Gowers, Levine, Bailey-Rogers, Shore & Burhouse, 2002) the study lacked the scope to establish a broader picture of the clinical effectiveness of the intervention by only using this measure, particularly as it is clinician-rated. The findings reported by Baier et al. (2013) were supported by a recently published study

by Duffy and Skeldon (2014), who also found significant improvements in overall functioning and mental health ratings post treatment, with the majority of post-scores falling out of the clinical range. However, this study received a fairly low quality rating score, and therefore conclusions should be made with some caution. For example, some participants received inpatient treatment during the study period although this was not accounted for or considered in the write up. This could suggest that the intervention on its own was not enough to support the participants in the study, and therefore pose the question about its effectiveness in preventing out-of-home placements.

The remaining three studies carried out retrospective evaluations of routine outcome measures collected at adolescent outreach services. Chia et al. (2013) found significant improvements in adolescents' overall functioning at discharge. They also reported significant decreases in re-admissions to hospital during the intervention and improved school attendance post-treatment (full-time attendance: 23% pre to 56% post). Chia et al.'s (2013) paper was let down by the lack of clarity in reporting about the large proportion of recruited participants whose data was not analysed, and whether this was due to the intervention being incomplete, and/or whether it reflected attrition rates. Without this information it is difficult to assess the potential of sampling bias.

Simpson et al. (2010) found similar findings, reporting significant improvement in overall functioning following treatment, with nearly 90% of cases achieving clinically significant change (i.e. 'clinical significance' defined as a change in score of four or more; Sharma, Wilkinson & Fear, 1999). Their measurement of clinical significance was a particular strength of the study, and an uncommon feature of the other studies in the review. In addition Simpson et al. (2010) found positive correlations between treatment duration and outcome,

indicating that longer treatment durations and greater number of clinical contacts were associated with better treatment outcomes. Findings from Schley et al. (2012) revealed client risk (to self and others) significantly reduced at discharge in conjunction with significant improvements in overall functioning and wellbeing. Interestingly, they also looked at the influence of engagement on outcomes, and found that better engagement following assessment was associated with reductions in hostility, wellbeing and functioning, but not suicide risk.

Overall the findings of these five studies point to significant improvements in psychological wellbeing and overall functioning post-treatment, suggesting that assertive community treatments are effective in treating young people with a range of severe mental health problems. There are several common limitations of the studies, however, that are important to note. A key issue is the research design: all utilised a one-group uncontrolled design. With the absence of a control or comparison group the positive findings of these studies cannot be attributed with certainty to the interventions under examination. In addition, none of the studies carried out follow-up evaluations, meaning that conclusions about the longer-term effects of the intervention, and whether clinical change is maintained, cannot be established. Moreover, three out of the five studies relied on retrospective evaluation (Chia et al., 2013; Schley et al., 2012; Simpson et al., 2010), which raises issues about the reliability of the data (e.g. accuracy of information recorded).

Wraparound services

Intervention characteristics

Wraparound services are community-based services for children with serious emotional disturbance and their families that aim to provide comprehensive approaches linking various agencies and services (particularly education and mental

health settings) to offer a complete system of care. It is viewed as a system-level intervention that quite literally aims to “wrap” existing services around young people and their families to address their problems in an ecologically comprehensive way (Solhkhah et al., 2007). Typically, a menu of different services is offered in addition to traditional outpatient treatment. These can include: 1) individualized care coordination, 2) respite care, 3) family support services, 4) skills building, 5) intensive in-home services, and 6) 24-hour crisis response.

Treatment outcomes

Three studies in the review evaluated wraparound services (Copp et al., 2007; Painter, 2012; Solhkhah et al., 2007), providing mixed results. Solhkhah et al. (2007) compared placement settings (e.g. home, residential, hospitalisation) of 169 young people before (i.e. 3.5 months average waitlist) and after completion of a wraparound treatment. Findings revealed that whilst on the waiting list 30% of the young people were maintained in the community, which was significantly less than 81% when enrolled in the treatment. Of the three studies evaluating wraparound services, Solhkhah et al.’s (2007) study was rated highest for methodological quality. Unlike most studies in the review, professionals received training on the program prior to study, enhancing its external validity. Other methodological strengths included the large sample size and use of a wait-list comparison group. Several limitations were also present, for example the authors refer to participants having received services whilst waiting for treatment without detailing what these were and how many participants they are referring to, which is likely to have impacted on the treatment outcomes. Furthermore there was no measurement of psychological symptoms and therefore the study was unable to assess the clinical implications of the intervention for the participants.

In a study evaluating the outcomes of a wraparound service at several follow-up time points, Painter (2012) found significant improvements across the range of outcome measures, indicating reduced behavioural problems and caregiver strain. These improvements were also maintained at 24 months follow-up. Interestingly, substantial differences were found between young person- and parent-rated measures: the young people rated themselves as having fewer behavioural and emotional problems prior to the intervention and did not show the same level of improvement as rated by parents. Painter's (2012) study scored points on Cahill et al.'s (2010) quality criteria for the use of treatment fidelity checks and low rates of attrition at follow-up (96% responders at 24 months); however, it was let down by the lack of a comparison group, limiting the extent to which the findings can be accounted for by the treatment.

Less positive findings were reported by Copp et al. (2007), who carried out an uncontrolled trial of a wraparound service as part of a wider study assessing the feasibility of a computer-based assessment tool. They found no significant differences in behavioural problems or psychosocial functioning for children and their families between baseline and six months follow-up. Copp et al.'s (2007) study was considerably poor in quality, rated the lowest amongst the full study set, and therefore the findings need to be considered in the context of this. High attrition rates meant a small sample was assessed (n=15) with no details of drop-out participant characteristics. Given the small sample size the use of parametric testing was inappropriate, posing risks to the study's internal reliability. Another important limitation of the study was the thin description of the intervention and professionals involved in its delivery.

Overall, a mixed picture emerges from these three studies of wraparound services. When taking into account quality of research design as a crucial factor in

drawing conclusions, however, the findings indicate promising results, both in terms of placement status and psychological and family functioning.

Multi-Systemic Therapy (MST)

Intervention characteristics

MST is an intensive home- and community-based family intervention designed originally for young people with serious anti-social behaviour (Henggeler, Schoenwald, Borduin, Rowland, & Cunningham, 1998). The intervention aims to reduce out-of-home placements by adopting a socio-ecological approach that intervenes at each key system around the child including home, school and community (Bronfenbrenner, 1979; Loeber, Stouthamer-Loeber, Van Kammen & Farrington, 1991). There is a growing body of evidence that supports the efficacy of MST for anti-social behaviour and youth offending (e.g. Curtis, Ronan & Borduin, 2004). In this review, however, the target population was young people with a primary mental health problem, as opposed to problems with delinquency. Several modifications have been introduced in order for MST to be used for patients with primary psychiatric problems, for example, including psychiatrists as part of the clinical team, increasing clinical supervision and reducing caseloads (Henggeler et al., 1999).

Clinical features include a comprehensive assessment of the young person, family, and the wider system (e.g. school), development of well-defined treatment goals, and implementation of specific manualised interventions (Henggeler et al. 1998). The typical caseload for each clinician is low, for example in Painter's (2009) study each clinician had four to six cases, allowing for a high level of contact with the families. Additional support is available in the form of 24 hours telephone support. The average intervention duration of the reviewed studies was between four

to six months. Interventions are delivered to the young person and their family within the home and community settings to enable generalisation of skills developed. Emphasis is placed on supporting parental involvement and enhancing parents' skills and strategies to effect change in the relevant domains (Butler, Baruch, Hickey & Fonagy, 2011).

Treatment outcomes

MST was evaluated by two non-randomised quasi-experimental studies (Painter, 2009; Stambaugh et al., 2007). Both studies reported favourable results for MST, and provided the most robust evidence within this review, as indicated by the highest average ratings on Cahill et al.'s (2010) quality criteria compared to the other studies. Stambaugh et al. (2007) compared MST to a wraparound service and a third group that received both MST and a wraparound service and found that the overall problem behaviour and psychological functioning of participants significantly improved from baseline to 18 months across all three groups. The MST-only group showed the greatest clinical change from baseline to 18 months. There were, however, no differences between the groups in terms of the rate of functional ability over the same time period. Stambaugh et al.'s (2007) study had several notable strengths, including an independent research team conducting data analysis, and the use of treatment fidelity measures for both the MST and wraparound interventions. Several important research limitations, however, need to be considered when interpreting the findings. Firstly, allocation to treatment group was non-randomised: the third comparison group (MST + wraparound) comprised participants who did not respond to either treatment type delivered on its own. It is unclear from the write up whether this was a planned or a post-hoc research decision. The findings are therefore likely to be biased, as those who did not respond to MST- or wraparound-

only interventions were not included in the respective groups analyses, and thus may be inflating the successful outcomes observed. Furthermore, the study used different inclusion criteria for each comparison group which is highlighted by their finding of significantly different baseline characteristics between the groups. The authors did, however, use baseline severity as a covariate in the analysis, in order to control for group differences at baseline.

The second study found similar results. Painter (2009) compared MST with treatment as usual (i.e. case management and family skills training) and found that a significantly higher number of young people in the MST group experienced clinically significant levels of improvement in mental health symptoms. Similarly to Stambaugh et al. (2007), however, no significant differences were found in terms of functioning. They did, however, find that those who received MST were significantly less likely to be involved in the juvenile justice system post treatment. The study received the highest quality score amongst the study set, with notable strengths including the use of treatment fidelity measures.

The overall findings from these two studies point to MST as being superior in improving psychological and behavioural symptoms; however, they indicate no significant improvements, compared to comparison groups, in overall functioning. The non-significant difference may in part be explained by the nature of the comparison treatment groups, which in both studies were also home-based interventions and thus likely to have influenced family and social functioning.

Intensive day treatment

Intervention characteristics

Day treatment programmes have been conceptualized as any programme that falls in the middle of the continuum of care between inpatient and outpatient

treatment (Topp, 1991). Typically these offer short-term, structured programs for children and young people, often in conjunction with support to the parents/carers, with delivery taking place within an outpatient setting. Two intensive day treatment interventions were evaluated within this review (Jerrott et al., 2010; Thatte et al., 2013). Thatte et al. (2013) evaluated a day programme for young people (aged 14-19 years) with severe mental health problems. The intervention followed a structured, multimodal 12- to 14-week day programme offering group therapy. Therapeutic interventions were offered on an individual basis (e.g. CBT, social skills training) by an interdisciplinary team, in addition to weekly community activities (e.g. bowling). The other day treatment programme, evaluated by Jerrott et al. (2010) targeted children aged five to 12 with a primary diagnosis of disruptive behaviour disorders. The short-term day programme was based on a cognitive-behavioural approach using token economy and skill building groups. Regular therapeutic groups were offered separately for children and parents by a multidisciplinary team of professionals, including a teacher to facilitate the children's return to full-time education.

Treatment outcomes

The quality of the two studies evaluating day programmes was mixed, with Thatte et al. (2013) receiving higher ratings, and therefore arguably providing more robust evidence. They found significant improvements in the young people's clinical symptoms and psychosocial functioning at discharge; however, at three months follow-up the magnitude of change was not maintained. The study was let down by the high attrition rates (e.g. 15 participants within the first two weeks of the programme, and 54 participants had incomplete data either because they dropped out or missed at least one assessment point), which poses questions about how acceptable the treatment was for the young people. The authors did, however, take

this into consideration, reporting no significant differences between completers and non-completers in terms of demographics and clinical symptom severity.

Similar findings were reported by Jerrott et al. (2010) who, using a non-randomised quasi-experimental design, found that compared to waitlist controls the intervention group showed significant improvements in their behaviour at home, presenting with less aggression and externalising behaviours. Additionally, significant reductions in parental stress and child-related stress in the treatment group were found. In a two and a half to four year follow-up study, the magnitude of treatment gains was reduced, indicating some degree of relapse (Clark & Jerrott, 2012). An area of strength in Jerrott et al.'s (2010) study was that all questionnaires were scored by a research assistant who was blind to the clinical status of the participants. This contrasted with several limitations on the design, for example the potential biasing of results given the opportunistic nature of the sampling where data was only analysed for children who had pre- and post-treatment measurements, therefore threatening the study's internal validity as data from participants who dropped out were not included in the analysis.

Given the substantial differences between the two day treatments reviewed, both in terms of targeted population and intervention delivery, it would be unwise to draw conclusions about intensive day treatment as a whole. Generally, however, both studies provide a similar pattern of results, in that positive outcomes were found at discharge yet improvements were not maintained to the same degree at follow-up.

Family preservation services

Intervention characteristics

Family preservation services are home-based intensive services for families who need additional support beyond typical outpatient services. One study (Lee et

al., 2009) evaluated a home-based family therapy intervention for children and young people with severe emotional and behaviour problems who were at-risk of out-of-home placements. The intervention was based on family therapy principles (e.g. Multi-dimensional Family Therapy (MDFT; Hogue, Liddle, Becker & Johnson-Leckrone, 2002); Brief Strategic Family Therapy (BSFT; Horigian et al., 2005)), taking a systems approach by collaborating with the different agencies involved with the family. Caseloads are relatively small, with about 10-12 families held by each clinician at one time.

Treatment outcomes

As part of a feasibility study, Lee et al. (2009) found a significant decrease in problem severity and increase in child functioning post-treatment that was maintained at six months follow-up, although there was a trend in reduced functioning and increased problem severity at six months post-intervention. Similar findings were reported for placement status, with only 5.1% receiving out-of-home placements during treatment, and 15.3% at six months follow-up. Lee et al.'s (2009) paper was based on an intervention development study, with the focus being on the theoretical underpinnings. The study was limited by the large discrepancies in the data set, ranging from 28 to 57 out of 77 full sets across the measures and raters (e.g. parent, worker, child). Lee et al. (2009) attempted to address this by conducting a multiple imputation method to simulate values for the missing data. A notable strength of the study was the use of a treatment fidelity measure that was rated by individuals independent of the delivery of the intervention.

In summary, only one study assessed the effectiveness of family preservation services, but it offers promising results. The lack of studies for this intervention may

be reflective of the targeted population, which has primarily focused on looked after children as opposed to a primary mental health problem (e.g. Chamberlain, 2003).

Discussion

Summary of main findings

The 13 studies in this review evaluated a range of interventions for children and adolescents with severe mental health and/or behaviour problems that are alternatives to inpatient psychiatric care. Studies were categorised according to the nature of the interventions delivered: MST, assertive community treatment, intensive day treatment, wraparound services and family preservation services. A common feature across the interventions was the focus on intervening at multiple levels of the young person's system by adopting a multi-agency and multidisciplinary approach. The interventions varied in duration (e.g. time-limited verses longer-term) and the targeted population (e.g. problem-specific verses global problem severity). Strengths of the study set as a whole included the generally high level of external validity, which was reflective of the clinical settings in which the interventions were evaluated, and the use of established child and adolescent outcome measures.

Overall, the studies provide promising evidence for the effectiveness of alternative care provisions to inpatient hospitalisation for children and young people with severe and complex mental health needs. Amongst the 12 studies that measured psychological functioning and behavioural problems, all but one (Copp et al., 2007) found statistically significant improvements following the intervention. All of the studies (n=4) measuring rates of out-of-home placements (including admission to psychiatric inpatient settings) also found significant improvements post-intervention.

The methodological quality of the studies varied, with several important limitations influencing the level of certainty that can be drawn from the findings. No

RCTs were included in the review, with the majority of studies using uncontrolled one-group designs. Although reporting was generally adequate, the description of principal confounders and key intervention components was generally poor. Very few considered clinical significance, making it difficult to determine the extent of meaningful change for the participants. Other key issues included the lack of follow-up data making it difficult to ascertain if the positive outcomes were maintained following discharge.

The five intervention types identified have commonalities in their target of the multiple levels of a child or young person's system (e.g. parent, school), and differences in terms of treatment duration and delivery approach. Assertive community treatment offers an intensive, flexible outreach support within the home and community settings to young people 'at risk' and 'hard-to-engage'. The focus of the intervention lies in building a strong therapeutic relationship and maintaining the young person in the community. Five studies of comparable quality evaluated this intervention type, with overall findings revealing significant improvements in mental health and functioning, and reductions in psychiatric hospital admission. These studies suffered significant methodological flaws, however, particularly with their use of retrospective analysis and lack of comparison groups. Follow-up studies are needed in order to see if improvements are maintained post discharge.

Wraparound services, which provide a community-based approach aimed at linking up the services involved with the young person, showed mixed outcomes. Two studies reported significant improvements in terms of placement status and psychological and family functioning, whereas another study found no significant changes in behavioural problems or psychosocial functioning between baseline and six months follow-up. Clearly there is a need for further research evaluating the outcomes, both short- and long-term, for wraparound services.

MST offers a manualised home- and community-based treatment to young people with anti-social behaviour (and more recently with young people with severe psychiatric problems) and their families. Clinical contact is high, and clinician caseloads are low. Of the five intervention types, MST yielded the strongest evidence based on Cahill et al.'s criteria (2010). Two non-randomised quasi-experimental studies found that MST is successful in reducing behavioural and psychological problems in young people with severe mental health problems, but it has less effect on overall functioning (e.g. social and family).

Two different intensive day treatments were evaluated within the review: one for children with disruptive behaviour disorders, and the other for adolescents with a range of mental health problems. The programmes offered structured, short-term group treatments delivered in clinic-based settings. Similar findings were reported for both programmes, with improvements found in targeted behavioural and psychological domains. Follow-up data for both programmes revealed that although improvements remained significant compared to baseline figures, this was of less magnitude compared to at discharge.

The final intervention type identified was a family preservation service for young people with severe emotional and behaviour problems at risk of out-of-home placements. The treatment was based on family therapy principles, with clinicians supporting a relatively small caseload. Promising results found reductions in problem severity and out-of-home placements post-treatment, but at six months follow-up these were not maintained at the same level (although continued to remain significant in comparison to pre-treatment outcomes). The study's strength lay in its inclusion of treatment fidelity measures; however, its high levels of attrition reduced the quality of the findings.

Overall the findings of this review are comparable to previous reviews (Shepperd et al., 2008, 2009). MST continues to receive the strongest evidence, scoring highest in terms of methodological rigour (Cahill et al., 2010). Positive outcomes were found across treatment models; however, mixed results were found in terms of follow-up measures. Since Shepperd et al.'s review (2009), no new RCTs evaluating alternatives to inpatient care interventions have been published. The majority of the evidence in the current review came from uncontrolled pretest-posttest designs, which poses important questions about the quality of the evidence that has recently been published. This issue is discussed in more detail below.

Methodological considerations

Given the variability in study quality and heterogeneity of target populations it is difficult to draw any firm conclusions about the interventions. Most of the interventions offered a flexible, individually tailored treatment package, making it difficult to ascertain what aspects of the intervention led to positive changes. Although several specific differences between the interventions can be identified, it is not possible to define the active ingredients within these interventions as each comprises a number of elements. Reporting of service delivery was variable, with many studies failing to report key features of the intervention, such as the duration or intensity of treatment, the staff involved or specific training requirements. Although flexibility in treatment delivery scored points on Cahill et al.'s (2010) quality criteria in terms of clinical representativeness, the high levels of heterogeneity within a given intervention has important implications for replication in future research and assessing treatment fidelity across studies. Similarly, little is known about the key components of inpatient care, with no clear definitions of what inpatient care offers in comparison to alternative treatment models. This appears crucial in determining

whether all services, including inpatient care, for young people with serious mental health problems offer similar therapeutic gains, or whether each treatment model offers something unique. Arguably research in this area is at the preliminary stages, with more research needed in teasing apart active treatment components.

Another central issue in the study set was the high level of heterogeneity in participants, with many treatments including young people being vaguely defined as 'high-risk' or 'at risk'. This prevents conclusions being made in relation to how we match treatments to problems in a 'what works for whom' fashion (Fonagy, Target, Cotterell, Phillips & Kurtz, 2002). Furthermore, given most of the treatments are systemic, both in terms of the impact of problems and the systems involved, sample characteristics and measurements in relation to family and school problems were scarce amongst the studies. It poses the question of whether the measurement strategies used in capturing outcomes from the interventions under study were adequate.

Moreover, the majority of the findings came from uncontrolled trials, which makes it difficult to interpret with any certainty whether the outcomes recorded can be explained by the intervention, or whether other extraneous variables are accountable for the changes. It is important to consider, however, that the nature of this clinical population, particularly the severity and nature of difficulties experienced, makes control groups practically and ethically difficult. Another important limitation amongst the study set was the lack of reported effect sizes. Most studies did, however, provide sufficient data (i.e. means and standard deviations) to enable the calculation of the magnitude of treatment effects. Related to this, few studies assessed clinical significance, making it difficult to determine the meaningfulness of change for the participants.

A promising finding regarding the quality of the studies was the almost unanimous use of multiple raters on the outcome measures (e.g. child, parent, clinician). This arguably provides a stronger basis on which to evaluate the impact of the intervention. It also reduces the risk of demand characteristics influencing the findings. Unfortunately, none of the studies produced any qualitative data, which would strengthen the overall findings of the interventions, and provide a perspective on the participants' experiences that cannot be easily captured by psychometric measures.

Limitations of the review

This review aimed to identify the range of interventions available to young people with complex mental health problems. Broad inclusion criteria were employed in relation to the target population (i.e. those with a serious mental health problem) in order to capture the spread of services in the literature. However, this may have led to the failure to identify specialist services that target specific populations or to the exclusion of such services in the review. For example, interventions for young people whose primary problem was delinquency and anti-social behaviour were excluded from the review. Given that MST was originally developed to support young people with serious anti-social behaviour (Henggeler et al., 1998) there is a substantial evidence base for MST with this population, which was not included (e.g. Curtis, Ronan & Borduin, 2004). Moreover, given the aim of the review was to evaluate interventions for children and adolescents, the target population age was limited to five to 18 years (or mean age falling within this range). This may have resulted in the failure to identify services for older adolescents who fall into the upper-age bracket. For example, Early Intervention for Psychosis Services (EIP) support young people aged 16 to 35 with prodromal and/or first

episode psychosis. Although EIPs are classified as preventative services, they could arguably be viewed as alternatives to inpatient care, as they provide intensive community support to young adults with severe mental health problems.

Furthermore, although Cahill et al.'s (2010) quality checklist provides an overall picture of a study's methodological strengths and weaknesses and offers a means to compare the quality of evidence across studies, it also has several limitations. The broad criteria arguably do not address several key factors relevant to the body of research in this review. For example, there is no consideration of multiple-perspectives in terms of outcome measures, which is particularly important in the current review given the nature of the interventions and the variety of potential informants involved (e.g. child, parent, school, clinician). Also, there is no criterion assessing whether studies have measured clinical significance, which is a crucial factor in understanding the extent to which identified change is meaningful for the participants. A further limitation of the checklist is the lack of attention to the length of follow-up measurement. In the study set of the current review some studies included 24 months follow-up assessments (e.g. Painter, 2012) while others presented follow-up data at only three months (e.g. Thatte et al., 2013). It could be argued that longer follow-up time frames yield stronger evidence.

Research implications

Arguably there remains a large amount of research to be done on assessing alternatives to inpatient care for children and young people. Unfortunately the issues raised in the previous review by Shepperd et al. (2009) remain: the evidence available in the literature offers limited guidance for the further development of these types of services. It is therefore crucial that improvements are made to the quality of the evidence base. Although established measures were used to evaluate the

interventions' effectiveness, it was rare that studies utilised the same measures. In order to allow for comparisons to be made of the differential effect of interventions, further research should focus on measuring outcomes using a few standardised instruments that have both clinician and user rated versions (e.g. HoNOSCA).

More research is needed to examine the longer-term outcomes of the interventions in order to assess whether the promising findings post-treatment are maintained. None of the studies in the review assessed cost-effectiveness, in order to establish whether the typically high levels of resource required in order to offer high intensity support outweigh the costs of out-of-home placements (including admission to psychiatric inpatient settings) which the services are aiming to prevent.

Further research could compare different models of alternative services in terms of effectiveness and cost, focusing on those services that are most prevalent, for example comparing assertive community treatment with intensive day treatment or wraparound services. In order to increase the ease of such comparisons, it may be that the development of services for specific disorders or problems is needed. Moreover, the use of qualitative research would allow us to understand the therapeutic mechanisms of change from the service users' perspective, as well as provide insights into the acceptability of the available interventions.

Clinical implications

Children and young people exist within systems that can both facilitate and hinder positive development and wellbeing. A key commonality amongst the interventions was the focus on targeting several of these systems (e.g. family, school). The high rates of attrition seen across the studies may be understood in the context of the target population, with engagement difficulties in adolescent groups being particularly prominent. Assertive community treatment is built on the premise

of therapeutic engagement as the key aim of the intervention. It is unsurprising, therefore, that those studies evaluating this intervention suffered fewer incidences of dropouts. There is some evidence within the current review to suggest that a strong therapeutic alliance early in treatment leads to better outcomes (Schley et al., 2012).

In recent years MST has received substantial high quality research attention in the form of RCTs. Unfortunately, however, other interventions covered in this review have not been afforded the same level of interest. It is likely that this is at least partly due to the strong theoretical underpinnings of MST compared to the other interventions, in addition to the focused targets for intervention which can be more readily captured (e.g. out-of-home-placements).

The lack of existing research has far reaching implications, particularly as service providers and commissioners require evidence-based information to inform the development of specialised services for children and young people with the most complex, severe or persistent mental health problems (McDougall et al., 2008). This is extremely pertinent given the current climate in the UK with ongoing cuts to the NHS as a cost-saving measure. The majority of the services evaluated in this review have a key objective of preventing admission to inpatient units and other out-of-home placements, which have huge cost-saving implications. Given the current state of the literature, however, such benefits may not be readily observable, further highlighting the fundamental need for better quality evidence.

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Part 2: Empirical Paper

Anticipating the transition from adolescent inpatient care back to the community: Young people's perspectives

Abstract

Objective: A small number of qualitative studies highlight both positive and negative service-user accounts of inpatient care. Little is known, however, about how the young person adjusts and reintegrates back home following discharge from an inpatient unit. Drawing on Self Determination Theory (Deci & Ryan, 1980), the present study aimed to explore adolescent inpatients' perspectives of the benefits and drawbacks of inpatient care, and specifically their expectations about their transition back into the community.

Method: Semi-structured interviews were conducted with 12 adolescent inpatients. Transcripts were analysed using thematic analysis in order to identify themes within the data.

Results: The young people described their experience of inpatient care as offering a mix of benefits (e.g. containment, supportive relationships) and drawbacks (e.g. living in a 'fake' world, lack of autonomy). The adolescents saw the transition back home as providing both opportunities and challenges: opportunities for personal growth and consolidation of the skills they had learnt to cope with their difficulties, while feeling unprepared to re-enter the "real world" after the experience of being "wrapped in cotton wool" on the unit, as well as concerned about how they would be perceived by others.

Conclusions: The inpatient environment has the potential to provide young people with person-centered care that addresses the key emotional vulnerabilities responsible for their admission to such specialised and intensive mental health intervention. Community teams should work closely with inpatient units to develop interventions that address the issues identified by young people as relevant to their transition home while promoting further development of the young person's newly acquired coping skills.

Introduction

Whilst the majority of adolescents receive support from mental health services in community settings, some have problems that reach a level of severity and complexity that requires admission to hospital. Adolescent inpatient units typically offer specialised assessment and intervention for young people experiencing severe mental health or behavioural and emotional difficulties, including psychosis, serious self-harm behaviours and anorexia nervosa (e.g. McDougall, Worrall-Davies, Hewson, Richardson & Cotgrove, 2008). The clinical aims are to reduce risk, or severity, of long-term psychopathology through the provision of an intensive therapeutic environment that has the potential to significantly impact on personality development (Cotgrove & Gowers, 1999).

There is an ongoing debate about the advantages and disadvantages of inpatient care across the lifespan. Key benefits proposed include the provision of intensive 24 hour assessment and support, the positive effects of a group milieu and the provision of safety to high risk patients (e.g. Green, 2002, 2006a). The disadvantages include high care costs, loss of contact and support from family and local community, and institutionalisation effects (e.g. Green & Jones, 1998; Sharfstein, 1985). Arguably this is further complicated for the adolescent population by a number of factors. Firstly, adolescence is a transitional stage characterised by the negotiation of key tasks such as an increase in autonomy and relationship development (Coleman, 1990); it is the interplay of these components that makes a significant contribution to the success or failure of the transition from childhood to adulthood (Carr, 1999). Crucially, significant or negative life events threaten this developmental stage, and can therefore influence an adolescent's identity (Erikson, 1968). An example of this is hospitalisation, which can disrupt normative development and impact on psychological wellbeing (Green & Jones, 1998;

McClowry & McLeod, 1990; Sharfstein, 1985). Secondly, stigma surrounding mental health issues is common in this age group. For example, in a recent UK study of a community sample of young people, 47% felt it was easier to tell someone if they felt physically unwell compared with feeling distressed or emotionally unwell (YoungMinds, 2010a). Stigma has also been reported as particularly prominent within the adolescent inpatient population (e.g. Martin, Pescosolido, Olafsdottir & McLeod, 2007; Wahl, 1999).

Intensive inpatient care is also costly and has high readmission rates (e.g. Larsen, 1991; Pedersen & Aarkrog, 2001). For example, a Danish study found that just under half of a sample of adolescent inpatients had been readmitted to hospital following their first admission (Pedersen & Aarkrog, 2001). Little is known about what happens after adolescents leave hospital, particularly from a service-user perspective, which could provide valuable information in understanding why readmission rates are high.

Effectiveness of adolescent inpatient care

There is strong evidence from a number of efficacy studies indicating that child and adolescent inpatient services are effective in terms of reducing clinical symptoms and increasing family functioning (Blantz & Schmidt, 2000; Green et al., 2007; Pfeiffer & Strzelecki, 1990). Reviews of these studies have concluded that inpatient care is beneficial, particularly if a specialised treatment programme and aftercare are available. Key aspects of treatment that predict good outcome include a good therapeutic alliance, problem-solving skills training and planned discharges (Blantz & Schmidt, 2000), and outcomes are generally better for adolescent inpatients with less severe clinical symptoms (Pfeiffer & Strzelecki, 1990). However, research evaluating adolescent inpatient care has mainly focused on

outcome data that relies on clinician-rated symptom levels, and most follow-up studies have focused on symptom outcomes as opposed to social functioning or quality of life.

Service-user perspectives

The importance of listening to service-users' accounts of their experience has been demonstrated in several areas of clinical research (e.g. Kitwood, 1997) and is a central aspect of many government initiatives (e.g. Every Child Matters, DfES, 2004). A recent consultation initiative by the Department of Health, "Liberating the NHS: No decision about me, without me" (DoH, 2012) promotes the importance of increasing service-user involvement and treatment choice.

To date, minimal research has investigated adolescent inpatient care from a service-user perspective. The limited number of studies surveying adolescents' experiences of psychiatric hospitalisation has found mixed results. Several surveys have shown that young people and their parents value the unit staff's availability and helpfulness, as well as the young people's relationships with fellow inpatients (Grossoehme & Gerbetz, 2004; Jones, Allen, Wells & Morris, 1978; Pyne, Morrison & Ainsworth, 1986; Tas, Guvenir & Cevrim, 2010). This contrasts with findings from a large-scale study produced by YoungMinds, a leading mental health charity for children and adolescents, that found that although 43% of young people found some features of inpatient stay helpful (e.g. daily activity programme, group therapy, and talking to staff), a large majority (70%) found many aspects of the experience unhelpful (e.g. boredom, emphasis on "problems" and "mental health", and length of stay) (Street & Svanberg, 2003).

Similarly, a small number of qualitative studies highlight both positive and negative service-user accounts of adolescent inpatient care. The experience of

‘containment’ provided by the inpatient unit, and the development of specific coping strategies have been reported as beneficial (Hepper, Weaver & Rose, 2005).

However, two recent qualitative studies reported mostly negative service-user experiences, for example feelings of restriction from the ward rules, witnessing aggression and restraint, and feeling disconnected from friends and family (Haynes, Eivors & Crossley, 2011; Polvere, 2011).

Qualitative research to date has primarily focused on exploring young people’s general experience of staying on an inpatient unit and what aspects of their experience were helpful. However, an important area that has not been addressed is the transition out of inpatient care following discharge and back into the community. The extent to which the adolescent successfully reintegrates back into their home environment following intensive therapeutic treatment is likely to have far-reaching implications in terms of their normative development and recovery (Green & Jones, 1998; McClowry & McLeod, 1990; Sharfstein, 1985). Understanding this process is particularly crucial given findings from a large-scale UK follow-up study that showed that a quarter of adolescent inpatients had not received any of the services recommended at discharge (Green et al., 2007). Service-user accounts about what they anticipate will facilitate and hinder their transition back home are needed in order to inform services how they can support this transitional stage.

Self Determination Theory

Self Determination Theory (Deci & Ryan, 1980) provides a framework for considering how the transition from inpatient care back into the community is experienced and negotiated by adolescents. The theory proposes three key mechanisms for the development of psychological well-being and motivation for positive self-initiated behaviour: competence (i.e. mastery and achievement),

relatedness (i.e. interaction and connection with others) and autonomy (i.e. sense of control over one's life). One of the main assumptions of the theory is that although optimal development and actions are inherent in humans, they do not happen automatically (Deci & Vansteenkiste, 2004); instead the individual's potential is actualised through nurturance of the social environment.

In light of the existing research on adolescents' experiences of inpatient care, it could be hypothesised that the inpatient environment offers both facilitating and compromising factors in the promotion of positive future behaviours. The sense of competence is likely to be facilitated by the development of coping strategies and skills to manage day to day situations (Grossoehme & Gerbetz, 2004; Hepper et al., 2005), yet reduced by limited opportunities to achieve, particularly in relation to educational goals (Haynes et al., 2011). Relatedness is likely to be compromised by the limited contact with family and friends, and feelings of isolation (Haynes et al., 2011; Street & Svanberg, 2003); however, it may be increased by the adolescents' relationships with fellow inpatients and the availability of the unit staff (Jones et al., 1978; Pyne et al., 1986; Tas et al., 2010). Finally, autonomy may be both promoted and compromised by inpatient care: adolescent inpatients have reported increased agency in their recovery (Hepper et al., 2005), yet have also described feeling restricted, living according to ward rules and routines (Haynes et al., 2011) and wanting more choice and involvement in their care (Street & Svanberg, 2003).

Rationale and aims of the current study

Adolescent inpatients are at significant risk of on-going mental health problems, difficulties in social functioning and unemployment into adulthood (e.g. Bobier & Warrick, 2005). Whilst admission to an inpatient setting reduces short-term risks (e.g. risk to self and others), little is known about post-hospitalisation

adjustment in the community. Understanding the experience of this transitional period from a service-user perspective has the potential to inform clinical practice in adolescent units and promote effective provision of care during the transition from the unit to the home environment.

The present study aimed to explore adolescent inpatients' expectations about their transition from inpatient care back into home and school. It focused on service-users' perspectives of the benefits and drawbacks of inpatient stay, and how these might help or hinder their return home following discharge.

A qualitative approach was chosen because it enables more complex aspects of human experience to be studied, including idiosyncratic beliefs and interpretations of events (Barker, Pistrang & Elliott, 2002). Semi-structured interviews were conducted in order to capture the potential complexity and variability of participants' experiences. Self Determination Theory (Deci & Ryan, 1980) was used as a framework to inform the interview schedule as well as the analysis of the data (Sandelowski, 1993).

The study addressed the following research questions:

- 1) What are adolescent inpatients' expectations about their transition from inpatient care back into the community?
- 2) What experiences of inpatient care do they anticipate will help or hinder this transition?

Method

Setting

The research took place at three adolescent psychiatric inpatient units in London. The units provided between 10-15 inpatient beds for adolescents aged 12-18 years old with acute and serious mental health problems, including major mood disorders, psychosis, eating disorders and emerging personality disorders.

Psychiatric assessment and treatment, both on an individual- and family-level, was provided by a multidisciplinary team, in addition to on-site education facilities. This is typical of treatment offered across adolescent inpatient units in the UK (O’Herlihy et al., 2001). The units differed in their treatment approach, with unit ‘A’ offering more of a therapeutic environment and longer treatment admissions (e.g. three months average stay) compared to units ‘B’ and ‘C’, which offered more crisis-led services with shorter admissions (e.g. one month average stay).

Ethical approval

Ethical approval for the research project was obtained from an NHS Research Ethics Committee via the Proportionate Review sub-committee (see Appendix B) and locally from the three inpatient units’ research and development departments (see Appendix C).

Recruitment

Participants were recruited from all three inpatient units. The target population was current inpatients who met the following inclusion criteria:

1. Aged 13-18 years, although the upper range of adolescence (i.e. 15-18 years) was targeted given the study’s focus on future aspirations.
2. A length of inpatient admission of a minimum of two months, in order to ensure that the young person had gained sufficient experience of inpatient stay.
3. Able to speak fluent English
4. Deemed well enough to participate by a member of the clinical care team (e.g. no symptoms of active psychosis) and without the presence of a significant learning disability or developmental disorder.

Eligible participants were identified by members of the care team at the respective inpatient unit. All eligible participants who met the inclusion criteria were invited to participate in the order in which they were identified. Where possible a purposive sampling strategy was employed in order to recruit a heterogeneous sample (e.g. mix of gender, age, and range of mental health problems). Recruitment ceased when little new information was emerging from the interviews, and a rich data set capturing the young people's experiences had been obtained (Strauss & Corbin, 1998).

Eligible participants were initially approached by a member of the inpatient unit's care team and informed about the study. Those who expressed an interest in the study were then approached by the researcher, who provided written information about the study for the young person and a separate information sheet for their parents/carers (see Appendices D and E). This information provided details about the nature and purpose of the study, as well as highlighting that it was part of an independent research project and would have no bearing on their care at the inpatient unit. Interviews were arranged at a time that was convenient for the participant once signed parental consent had been obtained. Signed consent from the participant was obtained on the day of the interview (see Appendices F and G for copies of participant and parental consent forms).

Participant characteristics

Of the 19 eligible participants, 12 consented to take part in the study, three were discharged before interviews were undertaken, and four declined. The main reason given for declining to take part was not feeling sufficiently emotionally stable to talk about their experiences.

The characteristics of the participants are shown in Table 1. Ten girls and two boys took part. The mean age was 16 years 3 months (range: 14 years 3 months to 17 years 6 months). There was a spread of mental health diagnoses amongst the participants, with eight having more than one diagnosis. Seven participants were recruited from unit 'A', four from unit 'B' and one from unit 'C'. The mean length of stay was just under three and a half months (range: 2 months to 8 months), but the modal length of stay on a unit was two months.

Interview

A semi-structured interview schedule (see Appendix H) was developed based on published guidelines on qualitative methodology (e.g. Smith, 1995). During the development stage of the interview schedule, consultation was sought from YoungMinds, a leading charity for child and adolescent mental health. Given YoungMinds' position in generating influential qualitative research about young people, it was thought this guidance would strengthen the quality of the study by ensuring that the interview schedule was deemed appropriately and adequately able to capture useful information. The semi-structured format of the schedule was chosen in order to allow the interviewer to remain flexible and follow-up on potential themes that were emerging during the conversation with the participant.

The interviews explored the young person's journey of staying on an inpatient unit, with a focus on the transition between the inpatient unit and returning back into the community following discharge. The three key mechanisms proposed by the Self Determination Theory (Deci & Ryan, 1980) required for positive future-orientated behaviour were used as a framework to guide the question domains (i.e. competence, relatedness and autonomy). These were applied loosely and adapted to fit the study setting and target population's language and understanding. To begin

with the context surrounding their admission to the inpatient unit was explored, followed by their experience of staying on the unit and how this compared to home life, with a particular focus on relationships, education and independent living skills. Following this, issues relating to stigma were explored, before finally focusing on their perceptions of leaving the unit and views of how things would be for them in the future.

The interview schedule was used flexibly, with the interviewer initially focused on building a rapport with the participant. Open and non-directive questions were asked as much as possible in order to limit the influence the interviewer had on the answers given by the participants. At times more directive questions and follow-up probes were required in order to clarify themes that were emerging and ensure that rich descriptions were obtained.

Each interview lasted approximately one hour. All of the interviews took place at the respective inpatient unit in a quiet interview room, and took place, where possible, towards the end of the participant's inpatient admission when a discharge date had been set. This was in order to capture the participant's perceptions about discharge and their ideas about what it would be like to return to the community.

At the end of the interview participants were given a £10 gift voucher to thank them for their time. They were also encouraged to speak to an allocated inpatient unit staff member if any upsetting issues had arisen during the interview. Prior to taking part the participants had given consent that if the interviewer felt concerned about issues relating to risk raised by the participant they would communicate this with their care team. No specific issues related to risk were identified, however, during the interviews.

Table 1: Characteristics of participants

Participant number	Gender	Age (years, months)	Mental health diagnosis	Length of stay (months)	Inpatient unit
1	Male	17, 11	Paranoid Schizophrenia	3	A
2	Male	15, 7	Bipolar Disorder	4	A
3	Female	16,5	Anorexia Nervosa	8	A
4	Female	15, 7	Attachment Disorder, emotion dysregulation	6	C
5	Female	16, 7	Psychosis, Asperger's Syndrome	3	A
6	Female	17, 6	Emotion dysregulation, Depression	2 ½	B
7	Female	17, 5	PTSD, OCD, Emerging Borderline Personality Disorder	4	B
8	Female	14, 3	Depression, Anxiety, PTSD	2	A
9	Female	16, 3	Anorexia Nervosa	2	A
10	Female	14, 11	PTSD, emotion dysregulation	2 ½	B
11	Female	16, 6	Anxiety, emotion dysregulation	2 ½	A
12	Female	17, 6	Emerging Borderline Personality Disorder	2	B

Analysis

All interviews were audio-recorded and transcribed verbatim (eight by the researcher and four by volunteer research assistants). Braun and Clarke's (2006) method of thematic analysis was used to identify pertinent ideas and patterns of responses that emerged from the data set. Thematic analysis is considered a flexible approach that is largely independent of epistemology and theory (e.g. Howitt & Cramer, 2007). It is a popular method of analysis that offers a coherent and rigorous set of procedures for qualitative data analysis. The stages of thematic analysis outlined by Braun and Clarke (2006) were adhered to. This involved the following process: (1) the familiarisation of the data set by the researcher, who transcribed and then re-read the transcripts, (2) the development of codes that described features of the data relevant to the research questions, (3) the grouping of codes to generate initial themes, which produced an initial thematic map, (4) the checking and verifying of themes across the data set, (5) further analysis and synthesising of the data in order to refine, review and name the themes, and (6) the selection of quotations from the transcripts to illustrate the themes and provide a rich description of the data. Appendix I shows examples of the stages of analysis.

The process of developing the final set of themes was informed by the frequency of relevant material both across the data set and within individual transcripts. Although most themes were supported by data from all participants, some applied to only a subset of participants; in the latter case, a theme was included if it captured a central aspect of those participants' experiences.

Credibility checks

The study was guided by established criteria for qualitative research in order to ensure that it was conducted in a systematic and rigorous way (e.g. Barker &

Pistrang, 2005; Mays & Pope, 2000). All of the interpretations and generated themes were grounded in the data, which was achieved by the researcher sticking closely to the transcripts during the coding and development of initial themes. Credibility checks were carried out in order to verify the themes identified (Barker & Pistrang, 2005). This involved the thesis supervisors (one an expert in qualitative research and the other in child and adolescent research) reading the transcripts and reviewing themes so that a consensus on coding was reached.

Researcher perspective

Given the subjective nature of qualitative research, the validity of the analysis is enhanced by the disclosure of the researcher's perspective (Caelli & Mill, 2003). My interest in adolescent mental health arose from my Assistant Psychologist post prior to training where I worked in an adolescent outreach team that worked closely with an adolescent inpatient unit. The development of my research question came from working in a team whose main remit was to prevent inpatient admission and maintain the young person in the community. It is likely that this, at least initially, influenced my approach to the interviews and reading of the data (Harper, 2008), for example anticipating that the participants would view their inpatient experience in a primarily negative way. However, I attempted to reflect on and "bracket" my own beliefs and assumptions, which was facilitated by working closely with my thesis supervisors during all stages of the research process (Ahern, 1999; Fischer, 2009). It was important, however, to acknowledge my prior clinical experience rather than to discount it completely, as it enabled some interpretive insights that added to the clinical discussion and implications (e.g. Fischer, 2009).

Results

The analysis generated 16 themes which were grouped into five superordinate themes (Table 2). A brief contextual overview is first provided in order to orient the reader to the data, followed by a detailed summary of each of the themes along with supporting quotations. Participant numbers are given with each quotation (e.g. P1) to denote speakers (see Table 1).

Overview and context

For nine of the 12 participants this was their first admission to an inpatient unit, whereas for three (P1, P6 and P12) it was their second. Although the specific circumstances surrounding the participants' admissions varied in detail, there were several key factors shared by all of them. Participants reported that their problems had been "spiralling out of control" and that they had lacked the appropriate strategies (if any at all) to cope. Many had felt isolated and alone with their problems, often as a consequence of family breakdowns following high levels of concern and stress. Over half of the participants had been deemed a significant risk to themselves, with many engaging in serious self-harming or risk-taking behaviours and experiencing active suicidal ideation.

Overall, the majority of the young people felt that their stay at an inpatient unit had been beneficial. Most said that early on in their stay they had been against it, but over time had begun to value their experience and benefit from the unit. All of the participants felt that their lives would have turned out very differently if they had not come to hospital, with the majority predicting that they would not have been alive.

Themes from the interviews

The five superordinate themes, each with their constituent themes, are presented in turn. The first two superordinate themes focus on the perceived benefits (and some drawbacks) of participants' stay on the inpatient unit, and a third captures the personal changes that the young people identified through their experience. The final two superordinate themes concern the transition from the unit to "normal life".

Table 2: Summary of themes

Superordinate themes	Themes
1. Feeling understood by others	1.1: A shared experience 1.2: "I can always talk to someone" 1.3: "A special person"
2. "A fake world"	2.1: "A substitute family" 2.2: Structure and routine 2.3: "Wrapped in cotton wool"
3. Feeling stronger	3.1: "A new me" 3.2: The bigger picture 3.3: Can I do it for myself?
4. Road to recovery	4.1: I still have problems 4.2: "One step at a time" 4.3: I need others to help me 4.4: "Back to square one"
5. Getting back to normal life	5.1: "Culture shock" 5.2: Will I be seen as normal? 5.3: Using my experience in a positive way

1: Feeling understood by others

A central experience reported by all of the participants was the importance of feeling understood by the other young people and staff in the inpatient unit.

Theme 1.1. A shared experience

All participants talked about how important it felt to have finally met other young people who really knew what it was like to have mental health problems, and who “got it”. Many sought comfort in sharing their experiences with the other young people on the unit:

When I talk to [a fellow inpatient] about my experiences I feel that they know what I'm taking about and that they've been through a similar sort of situation. (P8)

Knowing that they were not alone and that others were going through similar difficulties enabled the young people to develop strong connections with their fellow inpatients and experience a sense of validation and acceptance:

Most young people have had similar experiences as I have had... They know what you are going to be feeling about it and how to get over it if they have got over it themselves. (P10)

Some talked about the unit staff having little shared experience in terms of mental health problems, yet this wasn't seen as a problem as they felt that staff made an effort to understand them:

I share [my experiences] with the psychiatrist. And even though she doesn't relate to me, she's never been through what I've been through, she still kind of tries to understand. (P8)

The participants' experience of feeling understood and having common ground at the inpatient unit was strikingly different to their experience of home and

in the community, where the majority had felt judged and criticised for having difficulties. They believed this important contrast between the inpatient unit and home related to a lack of understanding of mental health problems outside of the inpatient unit, which many suggested derived from an absence of experience and knowledge:

If people don't understand what we've been going through they will judge it.
(P9)

It's difficult for people to help you if they have no idea what's going on.
(P12)

Although living with other young people with similar difficulties was seen as an important and positive aspect of their experience, some commented on the challenges that could also arise, for example being around others when they were distressed, particularly those whom the participant had developed a close relationship with. Several participants felt that they wanted to help others when they were struggling, sometimes at the expense of their own wellbeing:

It's kind of hard to concentrate on yourself when you see other people struggling and you want to help them, but you can't do anything about it.
(P2)

A number of participants from inpatient unit B talked about how witnessing others distress could “trigger” their own distress, and how this could sometimes lead to a snowballing effect ending with several inpatients struggling at the same time:

That's the only problem, you put a load of people with problems together you're going to trigger each other off. (P6)

Theme 1.2. “I can always talk to someone”

A key experience of the inpatient environment was that there were people around “*twenty four seven*” (P4) to talk to. Whether it was another young person or a staff member, there was a sense that “*I can always talk to someone*” (P10), which provided the young people with a crucial source of containment.

The participants valued talking to the staff at the unit. Many spoke about the staff’s persistent approach in supporting them: they would keep encouraging and “*not give up on me*” (P1), even when the young person was really struggling. The young people also valued the staff’s expertise and advice, with many feeling that the staff really knew what would help them. Several young people valued their relationship with staff on both a professional (i.e. providing expertise and advice) and a personal level (i.e. informal chats).

This contrasted greatly with the majority of the young people’s experience prior to admission, where they felt there was a lack of people to talk to. This often resulted in feeling isolated and alone with their problems:

I think most of the time, I felt worthless and like I didn’t really have anyone to talk to. I couldn’t even talk to my mum. I couldn’t even talk to my friends.
(P5)

However, for some of the participants the “*twenty four seven*” support felt too much, particularly at times when they wanted to be on their own:

No one has time to spend alone, because as you can see all these doors are locked. You can’t go into your bedroom... the only place you could possibly have all by yourself is the loo. (P6)

Theme 1.3. “A special person”

Most of the young people talked about developing a significant relationship with either a fellow inpatient or staff member during their time on the unit. This relationship played a crucial role in the young person’s experience, with several referring to it as being a “*life saver*” (P3). This “*special person*” (P4) served to create a sense of unconditional support, regardless of how unwell the young person was or had been. The young people talked about a deep connection with their significant other that had helped them to feel fully understood and cared for.

I became friends with [fellow inpatient] and things have been on an upward cycle since then. She has saved my life and I feel like everybody needs someone like that when they come to an environment like this. (P3)

For most of the participants, the significant relationship they developed was with a fellow inpatient. The key factor that tended to bring two people together was their shared experience, which increased the empathy they felt towards one another. Some participants’ significant relationship was with a staff member:

The [staff member] I was attached to... I just particularly felt like I could talk to her... I think she just stood out for me and I found someone special in her. (P4)

2: “A fake world”

All of the young people felt that the inpatient environment was completely different from their home life or “*the outside world*” (P4, P9). For several participants it was like “*a fake world*” (P3, P4, P7, P10, P11), which had its advantages and disadvantages.

Theme 2.1. “A substitute family”

The intensity of the inpatient environment meant that the participants felt they had developed strong bonds with several fellow inpatients and staff members on

the unit. Most compared the close relationships they had made with the other young people and staff on the inpatient unit to be like “*a substitute family*” (P3, P6):

Staff almost become your parents in the sense that they nag you sometimes and you've got to ask permission for things... And the patients almost become like brothers and sisters because you are so close. (P4)

For several participants this sense of closeness and cohesiveness with people on the unit contrasted with how things were with their real family at the time. They talked about how their real families were finding it difficult to cope, particularly in the lead up to their admission, and that this was having a negative impact on family relationships:

You don't want to talk to your parents about [your problems] because you don't want to upset them whereas with staff it's their job and they try to talk to you. (P11)

Although many valued having a close relationship with the other young people and staff members, several spoke about feeling uncomfortable that they had become “too attached”. They worried that this would make it harder for them to leave the inpatient unit and return home to their families:

I don't want to get comfortable because one day I will have to leave, and I want to be prepared when this day comes. I don't want to be really attached with this place because I will just get disappointed in the end... (P9)

One participant commented on how the comparison between their real parents and their “substitute parents” (i.e. staff members) was having a detrimental impact on their perception of and relationship with their real family:

P: I think that the staff, because you are spending so much time with them, especially when I was isolating myself from my family, a few of them became my substitute parents and I found it quite hard to disconnect...

I: And what impact do you think that had on your relationship with your parents?

P: I think it drove me further away from my parents and it made me feel like my parents were a bit inadequate in comparison. (P3)

Theme 2.2. Structure and routine

All of the young people talked about the high level of structure and routine on the unit. They were expected to adhere to a routine that involved attending education and therapeutic groups, with fixed meal times and bedtimes. This was a novel experience for many of the participants, who were used to doing “*what I wanted when I wanted*” (P5). At the time they had not realised how poor their routine was; it was only on coming to the unit and experiencing the significant contrast to home that brought about this realisation:

I think this place has made me realise how little structure I had cause you don't really notice, it's only when stuff changes you realise how bad it was before. (P6)

The majority of the young people valued the impact that having a clear and consistent routine had on their psychological wellbeing and management of difficulties. This helped them to keep busy and distract themselves from difficult thoughts and feelings:

Routine's important, it is necessary for managing yourself... the devil makes work for idle minds, but here you're always two minutes away from something else to keep you busy. (P1)

Half of the young people also talked about some downsides to the units' routine. Some spoke about how frustrating the lack of flexibility could be and how they weren't always able to do what they wanted to do. For example, several participants talked about having days where all they wanted to do was to lie in bed

and do nothing, but were “*forced to*” (P11) get up by staff and attend groups and other activities on the unit:

I know you have to do psychology and things like that but sometimes you just really don't want to...like being forced to do things that you don't want to do. (P11)

A minority spoke about how the strict regime of the inpatient environment felt as though they were being “controlled” by the unit staff. This left a few of participants feeling somewhat powerless and confined:

[Staff are] telling me what to do and [they're] in charge of my medication and [they're] literally in charge of... they're like in control of your life. (P6)

Theme 2.3. “Wrapped in cotton wool”

Feelings of safety and security on the inpatient unit were common amongst the young people, with one participant describing the experience as if she were “*wrapped in cotton wool*” (P4). All of the young people felt that the experience of safety and security was completely different to life outside of the unit, and offered both positive and negative aspects.

An important feature of the environment reported by all of the participants was the physical safety of the unit. Young people talked about feeling safe knowing that there was always someone around to manage situations as and when they arose, for example “*someone kicking off or getting really angry*” (P4). Many also talked about the ‘panic alarms’ which were used by staff to alert other staff members to an emergency or when assistance was required.

Over half of the young people had a history of self-harming behaviours or suicidal ideation. Common amongst them was the sense of safety they felt for themselves as a consequence of being on the unit:

We're being watched quite a lot of the time...I think it's quite good because I don't have a chance to hurt myself and I know I'm safe. (P11)

Another aspect of being “*wrapped in cotton wool*” reported by several young people was how the inpatient unit was a non-judgemental environment in which to practice skills that had been too difficult or frightening to do in the “outside world”, for example speaking out about their point of view, or socialising with others. This had enabled some of them to test out different ways of approaching situations with the reassurance that they would not be judged:

I feel like this is my safe zone where I can talk and I won't sound silly...when I say something people won't laugh at me. (P8)

Whilst on the whole the young people were pleased by the level of safety that the inpatient unit offered, some (particularly those with a history of self-harming behaviours) felt that their rights to harm themselves had been taken away:

Inside here everything is about your safety and risk management... sometimes it's enough to drive you insane, because obviously a lot of the time you don't want to be safe. (P12)

Similarly, several young people talked about how being in an environment that was safe and secure provided limited opportunities to deal with “real life” situations and to be able to cope on their own:

When you're out in the community you're exposed to everything whereas here you're not exposed to that. And it's frustrating because I wish I was. (P4)

3: Feeling stronger

All of the young people felt that from their experience of staying on an inpatient unit they had developed more confidence in themselves and their abilities to cope with their difficulties.

Theme 3.1. “A new me”

Participants described noticing positive changes in themselves, with many “feeling stronger” as a consequence of their experiences, particularly in comparison to how difficult things had been for them when they were first admitted. Participants also spoke about how they had developed a better understanding of their difficulties, and how this had helped them build a more positive self-concept:

[The experience] makes you a stronger person and you know a lot more about yourself, you know a lot more of what you’re capable of, what your body is capable of. (P3)

One participant highlighted the enormity of change she had witnessed in herself, referring to feeling as though she had been “upgraded” gradually during her stay on the unit:

All these little things all kind of add up to one big change that’s been like... I feel like I’ve been transformed in a way, like upgraded to a new me. (P8)

None of the participants felt that their experience of staying on an inpatient unit had altered their perception of themselves in a negative way. Some commented on how they had developed a more balanced perspective of themselves, that incorporated both their strengths and weaknesses. A common view was that the young people had begun to recognise their vulnerabilities, and how these might be more obvious to others given the fact that they were in an inpatient unit:

I think people have realised that I am a lot more vulnerable than they previously thought I was. (P3)

Theme 3.2. The bigger picture

The young people spoke about developing a new perspective or shift in perspective as a consequence of their inpatient experience. Many indicated that they had developed a sense of hope about the future as an outcome of their experience. For example, several young people had previously felt that they would not be able to cope and that things would continue to get worse for them, but since their stay at the inpatient unit had realised that “*no matter how hard things will get it does eventually get better*” (P3). Related to this, many of the participants felt a sense of achievement in “getting through” their time on the unit, and that if they could “survive it” and continue to function during such a difficult time in their lives they would be able to “get through anything”:

If I can still make friends in here, at my lowest point... then that's surely a good sign that I can be able to make friends [when I leave]. (P7)

Another change in perspective reported by several participants was that the things that would have bothered them before coming to the unit now appeared insignificant (e.g. whether they were wearing fashionable clothes). Going through the experience of inpatient stay had given some of the young people a “wake up call” about what was truly important in life:

[The inpatient experience] makes things in the outside world seem a lot more insignificant. So like, 'Oh my gosh, what am I going to wear to that party?... It's like, does it really matter?! (P3)

Furthermore, some of the young people talked about experiencing far-reaching changes in terms of their values and life goals as a consequence of coming to the unit, particularly in the area of education and academic success:

The thing is I've found out that there's more to life than just a degree, there is more to life than just a job. (P8)

Theme 3.3. Can I do it for myself?

Over half of the participants felt that they had begun to develop confidence in coping with difficulties on their own. During their time on the unit many had learnt strategies to manage their difficulties, with one participant referring to their newly acquired coping strategies as “*survival skills*” (P8). Several young people said they were confident that they would be able to use their skills to manage difficulties that would arise when they were no longer at the inpatient unit. Two participants talked about having a therapeutic skills “*toolbox*” that they would be able to make use of in the face of future difficulties:

I have the right tools and the right skills [that] I think will help me, like mindfulness and breathing exercises. (P1)

This contrasted with several participants who felt they had become increasingly dependent on others as a consequence of their inpatient experience. These participants suggested that the inpatient environment had reinforced their dependence on others, for example, the fact that even basic everyday activities such as going to the toilet required permission and facilitation by staff members:

I was quite an independent person... but here you got to rely on people because everything you do has got to be checked with staff members. (P4)

Several young people had begun to prepare for looking after themselves; recognising that although in this “*fake world*” there were staff around to do it for

them, they would soon be back in the “outside world” where they would need to do it for themselves:

There are times when you're pushing yourself...not just leave all of the looking after to other people... other people may be able to look after you for a bit, but you can't go on in life like that (P12)

This increased reliance of others left several of the young people feeling unconfident about how they would manage on their own when they did not have the support of the staff at the inpatient unit:

Doing things for myself... simple things like making food or doing your own washing...it's going to be difficult to get back into when you are so used to everything being done for you here. (P4)

4: Road to recovery

Most of the participants had been given their discharge date, and therefore had begun to imagine what it would be like to leave the inpatient unit and be back at home and at school.

Theme 4.1. I still have problems

Although the majority of the participants described significant improvements in their emotional wellbeing, all believed they would be leaving the unit with some ongoing difficulties. However, most suggested that their difficulties would be more manageable and have less of a detrimental impact on their lives:

I'll struggle in some areas [of emotional wellbeing] but I think they'll be a lot easier to get out of. (P10)

[I hope to] be able to live without some of the difficulties but even if they're not completely gone... just not as bad, not as hard [as before]. (P11)

Some of the young people reflected upon the “unpredictable” nature of their mental health problems and the impact this had in terms of making plans for the future:

You don't know whether you're going to be having a good day or a bad day, or even if you're going to have a good minute or a bad minute. (P6)

One participant felt that their mental health problems had actually become worse since their admission:

I know that when I get out of here, I'm not going to be mentally better...there's some things that've gotten worse since I've been in here. (P7)

Theme 4.2. “One step at a time”

In light of feeling that they would continue to have difficulties when they left the unit, a common aim in thinking about discharge was to take things slowly, “one step at a time” (P1, P3, P8). Several of the young people suggested that they were planning to focus initially on maintaining their own wellbeing and establishing a structured routine similar to the one at the unit and then reconnecting with their friends:

I'm just going to focus on doing stuff that will get my routine right first... And then, when I'm stable I will think about meeting up with my friends and stuff. (P1)

Most of the young people talked about a conflict between knowing it would be a better option to take things “one step at a time” yet also wanting to “pick up where I left off” (P3) and get back to how things were before their admission. This was a dilemma faced by several of the participants:

Before I was the sort of person that would jump straight into something... Now I'm thinking maybe I should take baby steps...it would be much easier than taking a big long jump and then breaking down again. (P8)

Theme 4.3. I need others to help me

Young people identified the need for others to continue to support them when they were discharged from the inpatient unit, including their family, friends, and community mental health teams. Although many felt more confident in their own abilities to cope with difficulties, they all acknowledged that they would not be able to do it on their own.

All of the participants reported feeling more confident in their family's understanding of their difficulties as a consequence of the support they had received at the unit. They felt that their families were now better equipped to support them appropriately and pick up on signs that things weren't going well:

Your family can pick up on difficulties quicker because they now know you better. (P3)

It was important for the participants to feel that when they were back at home they had a support network that knew them and understood their difficulties. This was particularly key for those young people who had felt isolated and alone with their difficulties prior to admission. Knowing that there would be people to support them gave them the reassurance that if difficulties emerged others would be there for them:

I now have people to support me, so... if something like this happens again there are people that I can talk to. (P5)

Participants talked about feeling comforted and reassured by the fact that they would continue to receive support from their community mental health teams following discharge, particularly given the “*twenty four seven*” support that they had become used to receiving at the unit:

[What helps is] knowing that I've got a good support network out there waiting for me. (P4)

Several participants talked about wanting to replicate the support they had received in the inpatient unit when they left. One participant was planning to find youth-based groups to attend in order to ensure that they continued experiencing support from a group setting. Another talked about hoping to find key people in their community who could replace the staff members and young people from the unit who had been significant in helping them:

It's going to be weird not having two special people there just for you... but then you have to find other people [in the community] that do care enough to be able to sit there and listen... (P10)

Theme 4.4. "Back to square one"

A key fear for all of the young people about leaving the inpatient unit was becoming unwell, being readmitted to the ward and therefore going "back to square one" (P1, P5, P7). They spoke about how this would be "devastating" and would indicate that they had not been able to cope with their difficulties. The prospect of returning to the inpatient unit symbolised a personal failure for the young people, with several suggesting that such an event would significantly impact on their confidence in their ability to cope:

I: What's your biggest fear?

P: That things will deteriorate and I'll end up back here. I'd see that as such defeat because you've battled for such a long time to get out and then you just end up back it's like you're starting back from square one. (P3)

Some of the young people went on further to say that they wanted to completely forget about their inpatient experience and almost "pretend as if it never happened" (P5):

This [hospital] kind of symbolizes everything that went wrong. Everything that went wrong that led to me coming here... So I kind of want to forget about it. (P5)

A small number of young people reported contrasting views about the prospect of being readmitted to the unit. Some worried that they would miss their experience of the unit so much that they would engage in behaviours that would result in them returning to the unit (e.g. suicide attempt). One young person had already pre-empted this concern and had established a plan for keeping in touch with staff members on the unit who had been significant during their experience:

I: What then are your biggest fears about leaving here?

P: Missing it! And wanting to come back! But I've already made a deal with my therapist in the community, that if I ever felt like coming back to see [staff member] that she would use her nursing powers to get me to speak to her. So that I didn't need to hurt myself to get back in. (P4)

5: Getting back to normal life

An important goal for all of the young people when they were discharged from the unit was to get back to “normality” and “*do things that normal teenagers do*” (P3). This was of central importance to all of the young people, who felt that their ability to be “normal” had been compromised to an extent whilst staying on the unit.

Theme 5.1. “Culture shock”

All of the participants expressed their concern about leaving the unit, predicting that it wasn't going to be an easy transition. Many talked about how it would be hard to adjust to the significant differences between the unit and their homes, with several participants anticipating that it was going to be a real “*culture shock*” (P3, P4, P6). Given that all of the young people viewed the unit as

completely different from their home life, many felt that they were not prepared for what they would have to face in the “real world”, particularly in cases where the young people had been staying on the unit for a substantial amount of time:

[The inpatient experience] doesn't prepare you for going back to normality... It's like we almost need tester trips, doing stuff where you're put back into normality but in a controlled way. (P6)

Some talked about the safety of the unit as a double edged sword; it provided a high level of security whilst they were on the unit, yet gave a “false sense of security” (P6) about the “real world” where they would be exposed to difficulties that they would not be prepared for:

I think you realise how much of not reality this is because you are so used to being so safe and everything, whereas when [I went on leave] I was petrified! And I think that's going to be really hard to get back into. (P4)

A small number of the young people expressed concerns about how they would cope without some of the key benefits to the inpatient experience, for example having people around “twenty four seven” to talk to, and how this would have a negative impact on their wellbeing:

[When] I go back I've got no one who's really close to me... You go from here where you see young people every single day, to back home and it's just you basically...then you're gonna start feeling a bit crap. (P7)

Theme 5.2. Will I be seen as normal?

All of the participants desperately wanted to be seen as “normal” by their friends and people in their community when they were discharged from the unit. The level of desperation was highlighted by one participant’s bargaining to be “normal”, who suggested that she would “chop off my right arm to be normal” (P6). The

young people worried about whether their experience of being on a psychiatric inpatient unit had negatively changed others' perceptions of them, and whether others would now think they were a "different person":

People might get worried in the sense that I'm not the same person anymore, that I'm different. But I don't want to be perceived as that. I just want to be normal. (P1)

Although there was a strong sense of wanting to reconnect with home friends, participants also expressed concern about how their friends might react to them when they were back home, for example, not knowing what to say or worrying about saying something that would offend them. Some worried that their friends might even avoid them as a consequence:

They wouldn't want to be close to me... they would want to stay away as far as possible from me. (P9)

Most of the young people also said they expected they would have to answer a lot of difficult questions when they returned to school, and worried about how they would be able to answer them. Again there was a concern that others would treat them differently and that they would be "*talked about behind my back*" (P9). Furthermore, all of the young people worried about the stigma attached to mental health problems and the lack of understanding amongst their peers, particularly those from school. A lot of them expected they would be labelled as "mental" or "psycho" if people found out that they had been on an inpatient unit. As a result, the participants had not told many people about their admission, instead keeping it quiet amongst a select few whom they felt would be more understanding:

[I haven't told many people I'm here] because people get this stereotype about people in mental health and I just don't want to be treated differently. (P11)

[My friend] told another person who she wasn't meant to tell and that person was like 'Oh, my God! She's gone psycho!... dadedada!' They don't understand. (P7)

Another important concern amongst several of the participants was the impact staying in an inpatient unit would have on their future career and employment opportunities. The majority said they would not want potential employers to know about their admission and mental health problems as they felt this would put them at a disadvantage over other candidates:

If you [and another candidate] were exactly the same apart from you having a mental disorder it's likely that [the employer] would choose the one without the mental disorder. Just so that they can have the peace of mind that they'll stay relatively sane for their job. (P7)

There was an underlying anxiety for many of the young people that they would be “found out” about their mental health problems and in particular their stay at a psychiatric inpatient unit.

Theme 5.3. Using my experience in a positive way

Although some of the young people wanted to forget all about their stay on an inpatient unit, the majority talked about wanting to use their experience in a positive way. Over half of the young people had decided to pursue a career in the helping professions and for most of them this decision was a direct consequence of their inpatient experience:

[When] I came here I sort of realised this is what I want to do and I can use my experience in a more positive way... I now want to be a psychiatric nurse in an inpatient setting. (P4)

Several of these participants talked about wanting to give something back to the mental health world, and felt that they would be able to offer other young people the sense of understanding and support that they benefited from and found to be a crucial aspect of their own inpatient experience.

Most of the young people talked about how their views of mental health and inpatient units had changed for the better as a consequence of their experience. Prior to their admission many identified with the stereotypes of “madness”, expecting to arrive at a hospital and be put in a “*straight jacket and fed lots of pills*” (P6) whilst lots of “*crazy people run around screaming*” (P5). Through their experiences the participants had learnt that people with mental health problems are “like everybody else”, which had not only impacted on their overall view of mental health, but also helped them to re-evaluate their beliefs about their own problems:

You come here and realise [a mental health problem] is not a bad thing, it can happen to anybody. And that makes it feel less harsh on yourself... it doesn't make me a freak, it doesn't make me any less of a person than anyone else who doesn't have a mental health disorder. (P3)

Discussion

This study explored young people's experience of staying on an inpatient unit, with a focus on their anticipations of the transition from inpatient care back to “normal life”. They described their experience of inpatient care as offering a mix of benefits (e.g. containment, supportive relationships) and drawbacks (e.g. living in a ‘fake’ world, lack of autonomy). The young people saw the transition back home as providing both opportunities and challenges. They saw it as an opportunity for personal growth and consolidation of the skills they had learnt to cope with their difficulties. The challenges of the transition included feeling unprepared to re-enter

the “real world” after the experience of being “wrapped in cotton wool” whilst on the unit, and concerns about how they would be perceived by others.

The experience of the inpatient environment

The young people’s accounts are consistent with the clinical aims of intensive person-centred care (Brunstetter, 1969; Cotgrove & Gowers, 1999). All of the participants highlighted how the intensive therapeutic nature of the inpatient environment provided a crucial source of safety and containment. A central aspect of this was the experience that there was always someone around to talk to. Participants valued the closeness of the relationships they had developed with their fellow inpatients and staff members, likening them to a “substitute family”. This suggests that a well-functioning inpatient environment encompasses similar nurturing properties of a well-functioning family (Dalton, Muller & Forman, 1989). Feeling understood by others, particularly fellow inpatients who had shared similar experiences, was a highly valued experience, and is consistent with previous studies of adolescent inpatient care (e.g. Grossoehme & Gerbetz, 2004; Tas et al., 2010). Participants also described good relationships with staff members, whom they felt were willing to listen and help. Research has shown that staff qualities such as being interested, understanding and devoting time to patients, correlate with high satisfaction levels reported by adolescent inpatients (e.g. Chung et al., 1995; Freed, Ellen, Irwin, & Millstein, 1998). This positive experience of feeling understood by others is particularly important given the link between patient satisfaction and positive outcome at follow-up (e.g. Elbeck & Fecteau, 1990).

The high level of routine and structure in the inpatient unit was experienced as having both benefits and drawbacks. Some participants found it confining and restrictive, whilst others felt it had supported their emotional wellbeing and coping

abilities. It has been proposed that a consistent routine in an inpatient unit establishes a system of predictable interactional patterns (e.g. mealtimes, community meetings, school, chores) that facilitates a sense of emotional equilibrium and enables the young person's entire day to be a therapeutic experience (Dalton et al., 1989). A key issue raised by the adolescents in the current study was the simultaneous struggle of needing others to support them whilst striving for autonomy and independence. Although this struggle is characteristic of the developmental challenge adolescents face (Coleman, 1990), it is possible that the highly structured nature of the unit may exacerbate the tensions between the need for adolescents to feel secure in their primary emotional relationships while establishing their own sense of identity and self-efficacy. On the other hand, it has been argued that adolescents need to establish a sense of dependency before being able to develop a more active role in their treatment (Hepper et al., 2005).

The transition: from inpatient care to the community

The participants viewed their upcoming discharge from the unit as both an opportunity for personal growth and a period of challenges. As a consequence of inpatient care the young people had begun to develop positive images of themselves and their abilities to cope. They therefore viewed the transition as an opportunity for further personal growth and consolidation of the coping strategies they had learnt. The perception of "personal growth" following inpatient admission has been reported in other studies (e.g. Hepper et al., 2005; Jones et al., 1978). Further follow-up research is needed, however, to establish whether adolescent inpatients maintain a sense of personal development post-discharge.

A key challenge identified by the young people was how the experience of being "wrapped in cotton wool" whilst on the unit might make it difficult to manage

‘real life’ situations after discharge. This has been raised by several authors, who suggest that the relatively controlled and dissimilar nature of inpatient environments compared to the inpatient’s home renders the young person unprepared to re-enter the community (e.g. Pottick, Warner, & Yoder, 2005; Pumariega, 2007). The adolescents also talked about the strong attachments they had formed to ‘unit life’ and how this would make their transition back home difficult. Again, this is consistent with previous research; for example, a qualitative follow-up study that interviewed young adults who had received treatment for eating disorders reported a dependence and attachment to inpatient care that evoked painful emotions on discharge (Offord et al., 2006). Such issues could be likened to the concept of ‘institutionalisation’, which was a major concern about inpatient care decades ago (e.g. Goffman, 1961). Whilst this view is typically perceived as outdated, the young people in the current study raised important issues about their ability to reintegrate back into the community following the intensive therapeutic experience offered by inpatient care.

Another challenge was the striking contrast between the relationships the young people had formed with their fellow inpatients, whom they described as being understanding and empathic, compared to the anticipated reaction from their peers in the community. Participants raised concerns about whether their ‘non-inpatient’ peers would view them as “normal”, or whether they would be seen as a “psycho” or a “mental” person as a consequence of their inpatient stay. Although it is possible that the participants were affected by elevated anxiety in the context of being discharged back into the community, there is also a reality to their concern, with research continuing to highlight the stigma surrounding mental health issues within the adolescent population (YoungMinds, 2010a). This is particularly important given that research that has shown that perceived peer rejection is a significant risk factor

for emotional maladjustment (Bowker & Spencer, 2010; Graham, Bellmore & Juvonen, 2003).

Self Determination Theory (Deci & Ryan, 1908) offers a theoretical framework to understand the accounts of the young people. The adolescents talked about issues that connected with each of the three mechanisms proposed for psychological wellbeing and positive future-orientated behaviours: relatedness, autonomy and competence. It could be argued that inpatient care presents an autonomy paradox for adolescents: it takes control away from the young person in order to provide safety and structure; however, the developmental process of the inpatient experience facilitates the young person's autonomy and transition into the community at discharge. Similarly with relatedness, the young people are taken away from their friends and family at home, yet have the opportunity to develop valued relationships with fellow inpatients and staff members on the inpatient unit. Furthermore, the adolescents develop a sense of competence through learning new ways to manage situations, which enables them to feel "stronger" in coping with their difficulties. In light of the findings of the study, and given the theory that optimal development is actualised through nurturance of the social environment (Deci & Ryan, 1980), it could therefore be suggested that the inpatient environment can foster several key mechanisms for adaptive development and thus create a platform from which the adolescent can develop positive future behaviours.

Limitations of the study

Several methodological issues need to be considered when interpreting the findings. It is likely that the young people who took part were a sub-group of adolescents who were willing to talk about and reflect on their experience, compared to the four young people who declined to participate due to their emotional

instability. Also, the process of inpatient staff identifying potential participants may have influenced the findings, for example, adolescents with more positive experiences may have been chosen compared to those with less positive experiences. Linked to this, the participants were predominately female, who presented with largely internalised problems (e.g. anxiety, depression). It is well established that individuals with internalising problems tend to be more reflective and introspective (e.g. Angold & Rutter, 1992); arguably the findings may have been different if more boys, who characteristically present with externalising problems (e.g. Lewinsohn, Hops, Roberts, Seeley, & Andrews, 1993; Zahn-Waxler, 1993), had taken part. However, the uneven balance of girls and boys also reflects the gender ratio reported in adolescent units nationally: a large scale project investigating the characteristics and use of child and adolescent psychiatric inpatient units in England and Wales found that female adolescents substantially outnumbered male adolescents (O’Herlihy et al., 2001). It could be suggested that inpatient units have developed care that is better suited to internalising problems given the higher proportion of females admitted. This is supported by the accounts of the young people in the current study, who imply that there is a good match between their vulnerabilities and the characteristics of the inpatient person-centered care.

Furthermore, given that the interviews required a certain level of verbal ability and comprehension, young people with poor verbal skills and impaired intellectual functioning were excluded. This may have impacted on the findings, as it has been shown that higher intelligence is associated with positive outcomes of inpatient care (Pfeifer & Strzelecki, 1990).

Another important consideration is the time at which the interviews took place. Interviewing young people at the end of their inpatient stay was deliberately chosen in order to capture their thoughts about their upcoming discharge and

transition back to the community. It is likely that the timing of the interviews influenced the participants' responses and abilities to stand back and reflect on their experiences (Luckstead & Coursey, 1995). Indeed, participants commented during the interviews that if they had taken part at the start of their admission they would have provided a more negative picture of their stay as they were still coming to terms with being admitted onto a unit and were struggling to cope. This suggests that where the young people are in terms of their inpatient stay (e.g. admission, middle, ending) will affect what we can learn. Arguably a strength of this study was interviewing the adolescent's towards the end of their stay, when they had a more comprehensive perspective on their treatment and were also able to comment on their upcoming discharge.

Other issues that relate to the generalizability of the findings are the small sample size and the recruitment of participants from London-based inpatient units. It should be noted, however, that the number of participants recruited was within the acceptable sample size range for qualitative studies (Creswell, 1999), and the representativeness of the findings is arguably strengthened by the recruitment from three adolescent units as opposed to a single unit.

Research implications

Both qualitative and quantitative longitudinal studies that follow up young people after discharge are needed to establish whether the perceptions reported near discharge remain the same when the young person is back at home and readjusting to "normal life". This could help answer some of the questions and concerns posed by the participants in the current study, about how they will cope with living back in the "real world" and renegotiating their friendships and day to day living.

Future research might also explore the perspectives of parents and other family members. In a qualitative study of parents' experience of their child being admitted to an adolescent unit, parents gave largely negative accounts, reporting that they felt unsupported by unit staff and excluded during their child's discharge process (Clarke & Winsor, 2010). Further research might focus on parents' and family members' experience of their child's discharge back home and what helps or hinders this process. This is particularly important given that families have a crucial role in facilitating recovery from mental health problems (e.g. Karp & Tanarugsachock, 2000; Sin, Moone, & Harris, 2008).

To date, limited attention has been paid to the social-developmental context of adolescent inpatient units, for example staff attitudes, the mix of patients and interpersonal dynamics on the unit, and the quality of staff-family-community interactions (Pfeiffer & Strzelecki, 1990). There is a need for further research to examine how environmental factors characteristic of adolescent units foster or inhibit psychological development during adolescence (Bronfenbrenner, 1979; Pfeiffer, 1989).

Moreover, Self Determination Theory (Deci & Ryan, 1980) could provide a theoretical framework for future research. The current study provides an example of how theoretical ideas can enhance qualitative research by informing the development of the interview schedule, as well as making sense of the data collected.

Clinical implications

A number of clinical implications are raised by the accounts of the young people in this study. Firstly, the young people showed a confident ability to reflect on their experiences and demonstrated a high level of self-reflection. This corresponds with other studies that demonstrate that young people are fully capable

of reflecting critically and astutely upon their experience of their care (e.g. Biering, 2009). Listening to adolescents' accounts enables them to have a voice in the planning of their treatment. Importantly it recognises their rights and acknowledges their developmental need to separate from their family and develop autonomy. It may be beneficial for inpatient units to foster and encourage adolescents' self-reflective capacity and ability to think of themselves as active agents within the overall therapeutic model (Hepper et al., 2005), particularly in relation to their discharge and making sense of their inpatient experience.

Secondly, a key aspect of the transition between the inpatient unit and home reported by the majority of the young people was their hope for continued support by community mental health teams after discharge. Follow-up provision of care is associated with positive outcomes of inpatient care (Pfeifer & Strzelecki, 1990), and the positive effects of inpatient treatment can easily be undone when aftercare services are not available (Durkin & Durkin, 1975). Given the intensive therapeutic nature of the inpatient environment, and the significant negative contrasts that the young people reported experiencing at home, it is paramount that adolescents are supported during the transition and long after their discharge. Crucially, community teams should work closely with inpatient units to support the generalisation of the young person's newly acquired coping skills when they return home.

Thirdly, the adolescent's feared being stigmatised and viewed negatively as a result of receiving such an intensive mental health service. They were particularly concerned about how their school peers would react to them, and what they might be saying about them whilst they were staying on the inpatient unit. Providing psychoeducation about mental health problems and available treatment options for young people in school settings would help to encourage open discussions and reduce the stigma surrounding mental health issues. This is particularly relevant in

education settings supporting the adolescent age group (e.g. sixth forms), given that the peak age of onset for developing a mental health disorder is 14 years (Kessler et al., 2005).

Concerns about inpatient care are well documented in the literature and have been highlighted as far back as the early 1980's (e.g. Knitzer, 1982). The findings from the current study, however, suggest that the inpatient environment has the potential to offer young people some of the fundamental psychological drivers for adaptive emotional development, for example containment of emotional distress, development of supportive relationships with others and feeling understood. Through this experience the adolescent may be able to develop more positive beliefs about themselves and their agency, which in turn may facilitate their transition from inpatient care and their ability to adjust to life in the community as a well-functioning member of society.

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Part 3: Critical Appraisal

Introduction

In this section I reflect on the process of developing and carrying out the research presented in Part 2 of this thesis. I highlight the importance of self-reflexivity in conducting research, particularly when the researcher has specific preconceived ideas about the subject matter being explored. I then reflect on the process of interviewing adolescent inpatients and factors that may have facilitated the process as well as some challenges that arose. Finally, I consider some of the tensions in balancing a phenomenological approach whilst being informed by a theoretical framework.

Self-reflexivity

Qualitative research aims to study people's perceptions and experiences in depth and detail (Barker, Pistrang & Elliott, 2002). It has been proposed that the researcher is the instrument for analysis across all phases of a qualitative research project (Starks & Trinidad, 2007). The subjective nature of qualitative research leads to the inevitable transmission of assumptions, values, interests, emotions and theories, which can influence how data is gathered, interpreted and presented (Tufford & Newman, 2012).

“Bracketing” is a technique that involves identifying and attempting to step aside from one's preconceptions in order to limit their influence on the research (Fischer, 2009). The extent to which bracketing is truly possible has been contested (Fischer, 2009; Tufford & Newman, 2010); it has been argued that the researcher's own ideas encourage thoughtful and reflective engagement with the data (Tufford & Newman, 2010). Self-reflexivity is a process that involves reflecting upon the ways in which ones' values, experiences, interests, beliefs, social identities and so on have shaped our research (Malterud, 2001; Willig, 2001).

Prior to clinical training I worked as an Assistant Psychologist for an adolescent outreach team. The service offered intensive community-based interventions to young people with severe mental health problems, with a key objective of preventing admission to hospital and maintaining the care of the young person at home and in their community. I came from a systemic and ecological perspective (e.g. Bronfenbrenner, 1992; Cecchin, 1987), viewing young people's difficulties as multi-determined and embedded within the systems around them (e.g. family, school, peers, community) which served to maintain their difficulties. I held the position that it is best to intervene within the contexts where the problems exist, for example the young person's home and school environments, as opposed to a new environment (e.g. an inpatient unit) in order for the young person and family to generalise their newly learnt skills. My experience of 'keeping young people out of hospital' inevitably shaped my views, and meant that I approached the research project with a number of negative presuppositions about the benefits and utility of adolescent units. For example, my presumptions were that inpatient care posed a significant and negative disruption to the young person's social and educational environment, and that the influence of contagion effects would exacerbate the adolescent's difficulties (Rhule, 2005).

I was mindful of the tensions that can arise between bracketing preconceptions and using them as insights (Finlay, 2008). Early on in the data collection process, on inspection of initial transcriptions, I realised that I was approaching the interviews intent on exploring the drawbacks to the adolescents' experiences of inpatient care, and often found myself pushing the young people to talk about negative aspects of their stay, even when this was not an issue that was being raised. Discussing my experiences and biases with my research supervisors enhanced my reflexivity and enabled me to consider how my preconceptions were

influencing the interviews and subsequent data set (Tufford & Newman, 2010). Through this process I adapted my approach to the interviews, taking more of a neutral and curious stance which allowed me to be more open to the adolescents' accounts.

Data analysis also posed a challenge, particularly as my presuppositions about inpatient care did not fit easily with the young people's accounts on the whole. At times during the analysis stage I noticed myself being drawn to aspects of the young person's accounts that highlighted the drawbacks of inpatient care. Whilst it was important to capture this within the analysis, it was also important to be aware of the risk of placing undue emphasis on certain views. Re-reading the transcripts helped me to ensure that I stayed close to what the young people had said, and discussing tentative themes with my research supervisors enabled me to form higher level conceptual ideas that remained embedded in the data set.

Self-reflexivity can be used not only to consider our position and prior experience during the development and implementation of a research project, but also to consider how the research may have affected and possibly changed us, as people and as researchers (Malterud, 2001; Willig, 2001). Through the process of hearing young people's experiences my views on inpatient care were significantly modified: having started out with preconceived ideas about inpatient care being largely negative and disruptive to the young person, I began to consider the benefits of such an intervention. I was struck by young people's accounts of the all-consuming nature of the inpatient experience, and how this offered the adolescents several fundamental psychological mechanisms for positive growth and recovery. Whilst I had been aware of the intensive therapeutic environment offered by inpatient settings, only on hearing young people's accounts was I able to fully appreciate what this meant to them and their recovery, leading me to re-evaluate my

position on the utility of adolescent inpatient care. This process showed me the impact that research can have on a clinician, and how being open to and ‘immersed’ in the data can allow you to substantially re-evaluate your views.

Interviewing adolescent inpatients

Many clinicians believe that adolescents are more difficult to interview than patients in other age groups (e.g. Coupey, 1997). It could be argued that adolescents with serious mental health problems pose an even bigger challenge. Whilst this may well be the case, the interviews with the adolescent inpatients in this study yielded a rich data set. There were several factors that may have facilitated this. Firstly, the semi-structured nature of the interview schedule offered flexibility that enabled key areas to be explored, but also allowed discussions to diverge in order to pursue an idea or response in more detail (Britten, 1999). During the development of the schedule I was mindful of my audience and tried to incorporate salient aspects of their experience that I anticipated they would engage with (e.g. education and friends). The interview deliberately began with questions that the young people could answer easily and then proceeded to more difficult and sensitive topics, such as issues relating to stigma, as the interview progressed (Britten, 1999). This helped put the young person at ease, build up their confidence in answering the questions, and establish a rapport with me as the interviewer (Gill et al., 2008).

Related to this, a second factor that may have facilitated the interviews was being able to draw on my clinical skills in working with ‘hard to engage’ young people. Maintaining a flexible, relaxed and interested approach during the interviews encouraged the young person to relax and in turn reflect on their experiences. It has been suggested that there are many similarities between clinical encounters and research interviews, in that both employ similar interpersonal skills, such as

questioning, conversing and listening (Gill et al., 2008). However, there are also some fundamental differences between the two, including the purpose of the encounter, reasons for participating and the roles of the people involved (Pontin, 2000). A challenge that any clinician will inevitably face when conducting research with clinical populations is the balance between their role as a researcher and their role as a clinician trained in therapeutic techniques (Orb, Eisenhaur, & Wynaden, 2000). There were times during the interviews that I felt drawn into ‘therapist mode’ and was tempted to respond based on my experience of working with high risk and vulnerable adolescents. At such times it was helpful to think about the use of bracketing in a clinical context, and that an important component of empathy is letting go of one’s own presuppositions, in order to understand what the client is trying to say (Barker et al., 2002). Moreover, drawing on my experience of working in a systemic and narrative model, which privileges a “not knowing” and radically curious stance to interpersonal interactions (e.g. Ekdawi, Gibbons, Bennett & Hughes, 2000; White & Epston, 1990) helped me maintain an engaging stance whilst supporting the participants in exploring a greater depth of feelings and meanings of their experiences.

Other factors that helped during the interview process included my age: research has shown that young service-users find it easier to talk to professionals who are closer in age to them (YoungMinds, 2011). Being in my mid-twenties may therefore have helped me to engage the young people, as they may have felt able to relate to me given my relatively youthful appearance and attitude. Similarly, their willingness to talk with me may have been facilitated by my deliberate attempt to spend additional time on the inpatient units during the data collection stage. I did this so that the young people could become familiar with my presence; when the occasion arose to invite the young person to take part in the study, they already knew

who I was and what I was doing. Furthermore, I found that being independent from the clinical setting offered the participants an opportunity to speak more freely and provide comments about issues they may have felt unable to make in the presence of staff members from the inpatient unit. It is possible that the young people's accounts would have differed in content if the interviews had been conducted by a member of the clinical team.

There is little research in the literature that addresses methodological issues of conducting research with clinical populations, in particular young people with severe mental health problems. During the research process I encountered several challenges when interviewing adolescents. One of the biggest challenges I faced was striking the balance between keeping within the overall aims of the study, whilst also exploring the nuances and idiosyncratic aspects of each young person's experience. At times I found myself becoming really interested and curious about a particular issue raised by a young person, even though it was outside of the focus of the research questions (e.g. the intergenerational experience of mental health problems). This highlighted the endless avenues that a researcher can take during the interview process, and the importance of having clear research questions to re-focus the discussion and exploration.

Related to the tension of knowing when (and when not) to explore a young person's utterances further, I noticed a developmental process in my interviewing skills. During initial interviews I had a tendency to stick rather rigidly to the interview schedule and ask limited follow-up questions, which arguably provided the young people with few opportunities to offer in-depth accounts of their experiences. This was reflected in the somewhat thin descriptions evident in early transcripts. As my confidence in interviewing grew, however, I began to be much more flexible in my approach, and stuck closer to what the young person was saying, inviting them to

expand on issues they were raising. This significantly benefited the data I was collecting, which was rich and vivid in description whilst still within the study's area of focus. I expect it was also more enjoyable for the young people being interviewed, who were given the opportunity to explore their experiences at a deeper level.

Another challenge during the interviews was paying close attention to the young people's language, and ensuring that I checked out their meaning of words, rather than being guided by my own assumptions. This was particularly important given the age of the participants, who often used slang or words that are not used in a conventional way (e.g. "sick" can refer to something that is 'really good').

An interesting and unforeseen aspect of the interview process was the discourse used by adolescent inpatients in relation to health care. For example, many of the young people referred to medical and psychological terms, such as "diagnosis", "in the community" and "triggers". In retrospect, this is not surprising given that they had been immersed in a medical/psychological environment for several months. However, this use of language contrasts to research presented by YoungMinds who found that young people prefer professionals to use jargon-free communication (YoungMinds, 2011). Given my own clinical experience and tendency to use jargon, it was important that I continually checked out that I understood the participants' meanings, instead of relying on my own assumptions and knowledge of clinical terms (Britten, 1995).

Qualitative data analysis and the incorporation of theory

The overarching aim of the current study was to explore young people's experiences and interpretations of inpatient care, and their anticipations and perceptions about their transition back home. I took a phenomenological approach, which privileges understanding individuals' lived experiences and world views

(Banister et al., 2011). I also drew on Self Determination Theory (Deci & Ryan, 1980) to provide a theoretical framework to make sense of the young people's accounts. Through the research process I became aware of several tensions in working phenomenologically whilst also incorporating a theoretical model.

Some argue that in phenomenology, "no preconceived notions, expectations or frameworks guide researchers" (Creswell, 1994, p. 94) and that researchers should be naïve to what has come before in order to be guided as much as possible by the data (e.g. Glaser & Strauss, 1967). Yet historically, qualitative research has been criticised for not being guided by theory in its development and conduct. The use of theory in qualitative research has been hotly debated (e.g. Creswell, 1994; Glaser & Strauss, 1967; Sandleowski, 1993), however, one strong argument is that drawing on theoretical frameworks is unavoidable and can help to guide and enhance the research process (Sandelowski 1993).

It has been proposed that a theory is 'a set of theoretical statements that provides an understanding and explanation about a class or classes of phenomena' (Kim 1997, p.31). The current study drew on Self Determination Theory (Deci & Ryan, 1980) as a framework to guide it, particularly in relation to the interview schedule and analysis of the data. My reason for choosing this theory was based on its relevance to the research questions: it focused on positive future behaviours and therefore offered a framework from which to examine the young people's accounts in relation to their anticipations in the transition back home. By incorporating a theoretical framework, I aimed to carry out a richer analysis, and one which provided illuminating insights into participants' accounts.

I was mindful of balancing a theoretical framework with the complex and rich descriptions provided by the young people, which I wanted to accurately represent first and foremost. Sandelowski and Barroso (2002) suggest that a common

problem in researchers' use of existing concepts and theories is that during data analysis the interpretations do not always fit well with the data. I was conscious not to be wedded to the theoretical framework I had chosen, but rather to use it to offer a deeper level of meaning to, and understanding of, the young people's accounts. I was aware of the risk that the adolescents' views could be distorted or concealed if I stuck too rigidly to the theory (Lugg, 2006); having regular discussions with my research supervisors during the analysis phase helped to make this tension explicit.

Qualitative research can be a laborious and time-consuming venture (Anfara & Mertz, 2006). The rich and vast amount of unstructured data posed a challenge that often left me feeling overwhelmed as I attempted to identify the central ideas being expressed. The use of theory helped to clarify my ideas, particularly as the young people were raising issues that connected with the key mechanisms proposed in the theory (i.e. relatedness, autonomy, competence). It could be argued that drawing on Self Determination Theory enabled the study to gain theoretical rigour, and for the study's findings to become more useful and comprehensible to those in other disciplines (Anfara & Mertz 2006). In this way, incorporating theory into qualitative research has benefits to both the researcher and the profession.

Conclusions

Qualitative research enables an in-depth exploration of complex human experiences (Barker et al., 2002). Listening to service-user views about their experience of treatment can have important clinical implications and can facilitate our understanding of key mechanisms of change (e.g. Kitwood, 1997). During the research process I was struck by the adolescents' abilities to reflect on their experiences and provide critical perspectives about inpatient care. Engaging in qualitative research has taught me the important contribution that service-user

accounts can make in our understanding of several psychological processes relevant to adolescent inpatients. The young peoples' accounts also illuminated several key aspects of inpatient care that may facilitate the transition back to the community.

Gaining an understanding from a service-user perspective can therefore offer helpful insights that have the potential to lead to better person-centered care.

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Appendix A

Cahill et al. quality checklist (2010)

Downs and Black rating sheet: Adapted version

ID

Reporting Yes = 1 No = 0 Unable to determine = 0

- | | | | |
|---|--|--------------------------|---|
| 1 | Is the hypothesis/aim/objectives of the study clearly described | <input type="checkbox"/> | |
| 2 | Are the main outcomes to be measured clearly described in the introduction or methods section | <input type="checkbox"/> | If the main outcomes are first mentioned in the results section, the question should be answered No |
| 3 | Are the characteristics of the clients included in the study clearly described | <input type="checkbox"/> | Inclusion and/or exclusion criteria should be given. Emphasis on inclusion and exclusion criteria, other characteristics are age/gender/morbidity |
| 4 | Are the interventions/treatments of interest clearly described? | <input type="checkbox"/> | Treatments and placebo (where relevant) that are to be compared should be clearly described |
| 5 | Are the distributions of principal confounders in each group of clients to be compared (or within a single group) clearly described? | <input type="checkbox"/> | A list of principal confounders is provided. Morbidity, co-morbidity, age, gender, previous history. Good qual will include adjustment regression or matching |
| 6 | Are the main findings of the study clearly described? | <input type="checkbox"/> | Simple outcome data (including denominators and numerators) should be reported for all major findings so that the reader can check the major analyses and conclusions. This question does not cover statistical tests which are considered below |
| 7 | Does the study provide estimates of the random variability in the data for the main outcomes? | <input type="checkbox"/> | In non normally distributed data the inter-quartile range of results should be reported. In normally distributed data the standard error, standard deviation, or confidence intervals should be reported. If the distribution of the data is not described, it must be assumed that the estimates used were appropriate and the question should be answered yes |
| 8 | Have all the important adverse events that may be a consequence of the intervention/treatment been reported? | <input type="checkbox"/> | This should be answered yes if the study demonstrates that there was a comprehensive attempt to measure adverse events (A list of adverse events is provided). E.g. early discontinuation of therapy |
| 9 | Have the characteristics of clients lost to follow-up been described? | <input type="checkbox"/> | This should be answered yes where there were no losses to follow-up or where losses to follow-up were so small that findings would be unaffected by their inclusion. This should be answered no where a study does not report the number of patients lost to follow-up.
Follow – up = post – therapy, or loss from study at baseline |

Reporting Yes = 1 No = 0 Unable to determine = 0

- | | | | |
|----|--|--------------------------|--|
| 10 | Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.01 | <input type="checkbox"/> | |
| 11 | Have sufficient data been provided to enable calculation of outcomes such as pre-post ESSs, estimates of reliable and clinically significant change | <input type="checkbox"/> | If data are provided to enable calculation of any one of these outcomes score the question yes |

External validity/clinical representativeness Yes = 1 No = 0 Unable to determine = 0

- | | | | |
|----|--|--|--|
| 12 | (a) Were the clients asked to participate in the study representative of the entire population from which they were recruited
(b) Were clients referred through usual clinic routes | <input type="checkbox"/>
<input type="checkbox"/> | The study must identify the source population for clients and describe how the patients were selected. Clients would be representative if they comprised the entire source population, an unselected sample of consecutive clients, or a random sample. Random sampling is only feasible where a list of all members of the relevant population exists. Where a study does not report the proportion of the source population from which the patients are derived the question should be answered as unable to determine |
| 13 | Were those clients who were prepared to participate representative of the entire population from which they were recruited? | <input type="checkbox"/> | The proportion of those asked who agreed should be stated. Validation that the sample was representative would include demonstrating that the distribution of the main confounding factors was the same in the study sample and the source population |
| 14 | (a) Were client heterogeneous in personal characteristics
(b) Were clients heterogeneous in terms of presenting problems | <input type="checkbox"/>
<input type="checkbox"/> | |
| 15 | (a) Were the staff, places, facilities where the patients were treated representative of the treatment the majority of patients receive?
(b) Was the treatment conducted in a non university setting
(c) Was implementation of treatment monitored (R) | <input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/> | For the question to be answered yes the study should demonstrate that the intervention was representative of that in use in the source population
The question should be answered no if, for example, the intervention was undertaken in a specialist centre unrepresentative of the hospitals most of the source population would attend |

External validity/clinical representativeness Yes = 0 No = 0 Unable to determine = 0

- 16 Were therapists experienced, professionals with regular caseloads
- 17 Were therapists free to use a wide variety of procedures in treatment and not just limited to one treatment procedure
- 18 (R) Were therapists trained immediately before the study and in the specific treatment being studied
-

Internal reliability Yes = 1 No = 0 Unable to determine = 0

- 19 If any of the results of the study were based on 'data dredging' was this made clear Any analysis that had not been planned at the outset of the study should be clearly indicated. If no retrospective unplanned subgroup analysis were reported, then answer yes
- 20 Were the statistical tests used to assess the main outcomes appropriate The statistical techniques used must be appropriate to the data. For example, non parametric methods should be used for small sample sizes. Where little statistical analysis has been undertaken, but where there is no evidence of bias, the question should be answered yes. If the distribution of the data (normal or not) is not described it must be assumed that the estimates used were appropriate and the question should be answered yes
- 21 Was the compliance with the intervention/s/treatments reliable? Where there was non compliance with the allocated the question should be answered no
- 22 Were the main outcome measures used accurate (valid and reliable) For studies where the outcome measures are clearly described, the question should be answered yes. For studies which refer to other work or that demonstrates the outcome measures are accurate, the question should be answered yes
- 23 Do the analyses adjust for different lengths of follow-up of patients in different treatment groups? Where no comparison group score 0. Where lengths of follow-up the same score 1

Internal reliability confounding (selection) bias Yes = 1 No = 0 Unable to determine = 0

24	Were the clients in different intervention/treatment groups recruited from the same population	<input type="checkbox"/>	For example, clients for all comparison groups should be selected from the same source population. The question should be answered unable to determine where there is no information concerning the source of patients included in the study. Where no comparison group score 0
25	Were the clients in different intervention/treatment groups recruited over the same period of time?	<input type="checkbox"/>	For a study which does not specify the time period over which clients were recruited, the question should be answered unable to determine. Where no comparison group score 0
26	Was there adequate adjustment for confounding in the analysis from which the main findings were drawn	<input type="checkbox"/>	This question should be answered no if the main conclusions of the study were based on analyses of treatment rather than intention to treat; the distribution of known confounders was not described; or the distribution of confounders differed between the treatment groups but was not taken into account in the analyses. If the effect of the main confounders was not investigated or confounding was demonstrated but no adjustment was made in the final analyses, the question should be answered no
27	Were losses of clients to follow-up taken into account?	<input type="checkbox"/>	If the numbers of clients lost to follow-up are not reported, the question should be answered as unable to determine. If the proportion of lost to follow-up was too small to affect the main findings, the question should be answered yes
28	Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%	<input type="checkbox"/>	Sample sizes have been calculated to detect a difference of x and y%. Has power analysis been performed
Size of smallest intervention group			
A			<N1 0
B			N1-N2 1
C			N3-N4 2
D			N5-N6 3
E			N7-N8 4
F			N8 + 5

Appendix B

Confirmation of NHS Research Ethics Committee Approval

03 June 2013

Study title: How does staying in an adolescent unit impact on how adolescents view their future?
REC reference: 13/SC/0181
IRAS project ID: 119313

Thank you for your letter of 31 May 2013, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Siobhán Bawn, NRESCommittee.SouthCentral-Oxfordb@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management

A Research Ethics Committee established by the Health Research Authority

permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		18 March 2013
Interview Schedules/Topic Guides	1.0	06 February 2013
Investigator CV		06 February 2013
Other: CV for Supervisor - Nancy Pistrang		06 February 2013
Other: CV for Student - Freya Gill		06 February 2013
Participant Consent Form	1.0, Parent	06 February 2013
Participant Consent Form: Parent/ Carer	2.0	17 May 2013
Participant Consent Form: Assent Form	2.0	17 May 2013

A Research Ethics Committee established by the Health Research Authority

Participant Consent Form: Young Person	2.0	17 May 2013
Participant Information Sheet: Parent/Carer	2.0	17 May 2013
Participant Information Sheet: Young People	2.0	17 May 2013
Protocol	2.0	17 May 2013
REC application	3.4	06 February 2013
Referees or other scientific critique report		08 October 2012
Response to Request for Further Information		
Summary/Synopsis	1.0	06 February 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/SC/0181

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely

Email: NRESCommittee.SouthCentral-Oxfordb@nhs.net

Enclosures: "After ethical review – guidance for researchers" [Emailed]

Copy to:

Appendix C

Local Research and Development Department Approval



Mental Health NHS Trust

05 July 2013

Dear Freya,

Research Title: How does staying in an adolescent unit impact on how adolescents view their future?
Principal Investigator: Miss Freya Gill
Project reference: PF566
Sponsor: University College London

Following various discussions your study has now been awarded research approval. Please remember to quote the above project reference number on any future correspondence relating to this study.

Please note that, in addition to ensuring that the dignity, safety and well-being of participants are given priority at all times by the research team, host site approval is subject to the following conditions:

In addition to ensuring that the dignity, safety and well-being of participants are given priority at all times by the research team, you need to ensure the following:

- The Principal Investigator (PI) must ensure compliance with the research protocol and advise the host of any change(s) (eg. patient recruitment or funding) by following the agreed procedures for notification of amendments. Failure to comply may result in immediate withdrawal of host site approval.
- Under the terms of the Research Governance Framework, the PI is obliged to report any adverse events to the Research Office, as well as the REC, in line with the protocol and sponsor requirements. Adverse events must also be reported in accordance with the Trust Accident/Incident Reporting Procedures.
- The PI must ensure appropriate procedures are in place to action urgent safety measures.
- The PI must ensure the maintenance of a Trial Master File (TMF).

Terms and conditions of Approval, version 1.1 05/07/2013

- The PI must ensure that all named staff are compliant with the Data Protection Act, Human Tissue Act 2005, Mental Capacity Act 2005 and all other statutory guidance and legislation (where applicable).
- The PI must comply with the Trust's research auditing and monitoring processes. All investigators involved in ongoing research may be subject to a Trust audit and may be sent an interim project review form to facilitate monitoring of research activity.
- The PI must report any cases of suspected research misconduct and fraud to the Research Office.
- The PI must provide an annual report to the Research Office for all research involving NHS patients, Trust and resources. The PI must also notify the Research Office of any presentations of such research at scientific or professional meetings, or on the event of papers being published and any direct or indirect impacts on patient care. This is vital to ensure the quality and output of the research for your project and the Trust as a whole.
- Patient contact: Only trained or supervised researchers holding a Trust/NHS contract (honorary or substantive) will be allowed to make contact with patients.
- Informed consent: is obtained by the lead or trained researcher according to the requirements of the Research Ethics Committee. The original signed consent form should be kept on file. Informed consent will be monitored by the Trust at intervals and you will be required to provide relevant information.
- Closure Form: On completion of your project a closure form will be sent to you (according to the end date specified on the R & D database), which needs to be returned to the Research Office.
- All research carried out within South West London & St George's Mental Health NHS Trust must be in accordance with the principles set out in the Department of Health's Research Governance Framework for Health and Social Care 2005 (2nd edition).

Failure to comply with the conditions and regulations outlined above constitutes research misconduct and the Research Office will take appropriate action immediately.

Please note, however, that this list is by no means exhaustive and remains subject to change in response to new relevant statutory policy and guidance. If you have any queries regarding the above points please contact [redacted] R&D Co-ordinator, on [redacted] [redacted] e-mail: [redacted]



NHS Foundation Trust

[Redacted box]

FINAL R&D APPROVAL

23 September 2013

[Redacted box]

Tel: [Redacted]
Fax: [Redacted]

Email: [Redacted]

Dear Dr [Redacted]

Protocol: How does staying in an adolescent unit impact on how adolescents view their future?

ReDA Ref: CB/1307/1
REC Ref: 13/SC/0181

I am pleased to inform you that the [Redacted] [Redacted] has approved the above referenced study and in so doing has ensured that there is appropriate indemnity cover against any negligence that may occur during the course of your project, on behalf of [Redacted] Trust. Approved study documents are as follows:

Type	Version	Date
Protocol	2.0	17 May 2013
Interview Schedule	1.0	06 February 2013
Flow Chart	1.0	06 February 2013
Assent Form	2.0	17 May 2013
Consent Form Parent/Carer	2.0	17 May 2013
Consent Form Young Person	2.0	17 May 2013
Information Sheet for Young people	2.0	17 May 2013
Information Sheet for Parent/Carer	2.0	17 May 2013

Please note that all research within the NHS is subject to the Research Governance Framework for Health and Social Care, 2005. If you are unfamiliar with the standards contained in this document, or the BH and QMUL policies that reinforce them, you can obtain details from the Joint Research Management Office or go to:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108952

You must stay in touch with the Joint Research Management Office during the course of the research project, in particular:

- If there is a change of Principal Investigator
- When the project finishes
- If amendments are made, whether substantial or non-substantial

This is necessary to ensure that your R&D Approval and indemnity cover remain valid. Should any Serious Adverse Events (SAEs) or untoward events occur it is essential that you inform the Sponsor within 24 hours. If patients or staff are involved in an incident, you should also follow the Trust Adverse Incident reporting procedure or contact the Risk Management Unit on 020 7480 4718.

We wish you all the best with your research, and if you need any help or assistance during its course, please do not hesitate to contact the Office.

Yours sincerely

Copy to: Sponsor Organisation



16 August 2013

I am pleased to confirm that the following study has now received R&D approval, and you may now start your research in the trust identified below:

Study Title: How does staying in an adolescent unit impact on how adolescents view their future ? R&D reference: IRAS ID 119313 REC reference: 13/SC/0181		
This NHS Permission is based on the REC favourable opinion given on 26 July 2013.		
Name of the trust	Name of current PI/LC	Date of permission issue(d)
<input type="text"/>	<input type="text"/>	16 August 2013
If any information on this document is altered after the date of issue, this document will be deemed INVALID		

Specific Conditions of Permission (if applicable)
If any information on this document is altered after the date of issue, this document will be deemed INVALID

Yours sincerely,

Appendix D

Young Person Participant Information Sheet

Information sheet for young people

How does staying in an adolescent unit impact on how adolescents view their future?

(Student research project)

Part 1

We are asking if you would like to take part in a research project that hopes to find out about your experience of staying in an adolescent unit, and in what ways this experience may have changed different areas of your life.

Before you decide if you want to take part in the study, it is important that you understand why the research is being done and what it will involve for you. So please read this leaflet carefully, and if it would be helpful talk to your family, friends, doctor or nurse about the study and whether you want to take part.

Why are we doing this research?

We would like to find out from you how staying in the unit has helped, or not helped, with your confidence in different areas of your life, for example your relationships with others and your ability to look after yourself. We are interested to know how staying on a unit may have influenced how you think things will be for you in the future, and whether this has changed since coming to the unit.

Why have I been invited to take part?

You have been invited to join our study because you are staying at an adolescent unit. The study aims to involve about 20 young people who are currently staying at an adolescent unit in London.

Do I have to take part?

No. Taking part is completely voluntary. You are free to stop taking part at any time during the study without giving a reason. If you decide to stop, this will not affect the care you receive now or in the future.

What will I have to do if I take part?

If you agree to take part in the study, we will invite you to meet with a researcher, Freya Gill, who will answer any questions you have about the study. If you are still interested, Freya will ask you to sign a consent form. You will be given a copy of this information sheet and your signed form to keep.

Freya would then talk with you about your experiences of staying in an adolescent unit, and your thoughts about different areas of your life (for example, family and friends, school, abilities, future plans). The discussion should last about 1 hour. It will take place in a quiet room in the adolescent unit. The conversation will be audio-recorded to make sure that we get an accurate picture of your experience. The discussion will be carefully written down by the researchers, and then the recording will be deleted.

Are there any risks in taking part in the study?

There are no major risks in taking part in the study. It is possible that you might find some of the questions a bit difficult to answer, for example, about your relationship with your family. If you become upset or feel uncomfortable at any point during the study we will stop the discussion. We have arranged that one of your care team would be available for you to talk

to if this happens. However we think it is unlikely that you will become upset whilst taking part in the study.

What are the possible benefits of taking part?

We hope that what we learn from this study may be used to help other young people staying in adolescent units, and help adolescent units think carefully about how they provide support to young people. You will be given a £10 gift voucher (for Amazon) for taking part in the study.

Thank you for reading so far – if you are still interested, please see Part 2 below.

Part 2

Further information you need to know if you want to take part in the study.

Who is organising the research?

This study is part of Freya Gill's doctoral clinical psychology studies. Your adolescent unit (along with other units in London) has agreed to take part in the study and suggest young people who they think might take part. This is the only involvement that your unit has in the research.

What other information about me would you collect?

We would also like to keep a record of your age, gender, mental health diagnosis and length of stay at the unit. This is to help us get background information about the young people who take part in the study. This information will be made anonymous, as it will be just attached to a number, and therefore no one will be able to identify you from the details we keep.

What happens with what I say during the study?

All the information you give is confidential. The written notes from your discussion and the other information we collect (see section "What other information about me would you collect?") will be carefully stored on a computer (password-protected). Our copy of the consent form will be stored in a locked office in the Research Department of Clinical, Educational and Health Psychology at University College London. Only the researchers involved in this study will have access to any of your information. We will not tell anyone (including your care team at the adolescent unit) what you talked about. We would however need to tell your care team (and other services if appropriate, for example emergency services) if you tell Freya that either you or someone else is at serious risk of harm.

We will keep your information (written notes from discussion, other information and signed consent form) for up to 5 years after the study is finished. After this time everything will be permanently destroyed. If you decide during the study that you want to stop, your details can be destroyed if requested.

Reporting the study findings

We will write a report about the study that will describe what all the young people involved in the study have said. We might use quotes of what you tell us during the discussion, but we will not include your name or any other information about you and your family that can identify you. Nobody else will know that you took part in the study.

If you would like to see a copy of this report when it is published, please speak to our Freya, who will give you details on how to do this.

Thank you for reading this.

Contact details

We would be very happy to answer any questions you have, so please contact us if you have any queries:

We can also be contacted at the following address:

Research Department of Clinical, Educational and Health Psychology, Gower Street, WC1E 6BT

If you would like to make a complaint about the study, please contact your local independent Patient Advice and Liaison Service (PALS) on (telephone number) or (email address).

Appendix E

Parent Participant Information Sheet

Information sheet for parent/carer

How does staying in an adolescent unit impact on how adolescents view their future?

(Student research project)

Part 1

We are asking if your son/daughter would like to take part in a research project that hopes to find out about their experience of staying in an adolescent unit, and in what ways this experience may have changed different areas of their life.

Before you decide if you agree to your son/daughter taking part in the study, it is important that you understand why the research is being done and what it will involve for them. So please read this leaflet carefully.

Why are we doing this research?

We would like to find out from young people how staying in the unit has helped, or not helped, with their confidence in different areas of their life, for example their relationships with others and ability to look after themselves. We are interested to know how staying on a unit may have influenced how young people think things will be for them in the future, and whether this has changed since coming to the unit.

Why has my son/daughter been invited to take part?

Your son/daughter has been invited to join our study because they are staying at an adolescent unit. The study aims to involve about 20 young people who are currently staying at an adolescent unit in London.

Does my son/daughter have to take part?

No. Taking part is completely voluntary. They are free to stop taking part at any time during the study without giving a reason. As their parent/carer, you are also free to decide whether or not they should take part in the study. If either you or your son/daughter decided to stop, this will not affect the care they receive now or in the future.

What will my son/daughter have to do if they take part?

If you and your son/daughter agree to take part in the study, we will invite your son/daughter to meet with a researcher, Freya Gill, who will answer any questions they have about the study. You will also be given the opportunity to speak to Freya if you required further information (please see contact details below). If you and your son/daughter are still interested, Freya will ask you both to sign a consent form. You will both be given a copy of this information sheet and your signed form to keep.

Freya would then talk with your son/daughter about their experiences of staying in an adolescent unit, and their thoughts about different areas of their life (for example, family and friends, school, abilities, future plans). The discussion should last about 1 hour. It will take place in a quiet room in the adolescent unit. The conversation will be audio-recorded to make sure that we get an accurate record of what was said. Afterwards, the recordings will be transcribed by the researchers, and then the recording will be deleted.

Are there any risks in taking part in the study?

There are no major risks in taking part in the study. It is possible that your son/daughter might find some of the questions a bit difficult to answer, for example, about their

relationship with their family and friends. If they become upset or feel uncomfortable at any point during the study we will stop the discussion. We have arranged that one of their care team would be available for them to talk to if this happens. However we think it is unlikely that they will become upset whilst taking part in the study.

What are the possible benefits of taking part?

We hope that what we learn from this study may be used to help other young people staying in adolescent units, and help adolescent units think carefully about how they provide support to young people. To thank your son/daughter for taking part, we will give them a £10 gift voucher (for Amazon).

Thank you for reading so far – if you are still interested, please see Part 2 below.

Part 2

Further information you need to know before you can decide whether your son/daughter should take part in the study.

Who is organising the research?

This study is part of Freya Gill’s doctoral clinical psychology studies. Your son/daughter’s adolescent unit (along with other units in London) has agreed to take part in the study and suggest young people who they think might take part. This is the only involvement that the unit has in the research.

What other information about my son/daughter would you collect?

We would also like to keep a record of their age, gender, mental health diagnosis and length of stay at the unit. This is to help us get background information about the young people who take part in the study. This information will be made anonymous, as it will be just attached to a number, and therefore no one will be able to identify your son/daughter from the details we keep.

What happens with what my son/daughter says during the study?

All the information they give is confidential. The written notes from the discussion and the other information we collect (see section “What other information about my son/daughter would you collect?”) will be carefully stored on a computer (password-protected). Our copy of the consent form will be stored in a locked office in the Research Department of Clinical, Educational and Health Psychology at University College London. Only the researchers involved in this study will have access to any of your son/daughter’s information. We will not tell anyone (including their care team at the adolescent unit) what they talked about. We would however need to tell their care team (and other services if appropriate, for example emergency services) if your son/daughter tells Freya that either they or someone else is at serious risk of harm.

We will keep your son/daughter’s information (written notes from discussion, other information and signed consent form) for up to 5 years after the study is finished. After this time everything will be permanently destroyed. If you or your son/daughter decides to stop participating details can be destroyed if requested.

Reporting the study findings

We will write a report about the study that will describe what all the young people involved in the study have said. We might use quotes of what your son/daughter tells us during the discussion, but we will not include their name or any other information about them and their family that can identify them. Nobody else will know that they took part in the study.

If you would like to see a copy of this report when it is published, please speak to Freya, who will give you details on how to do this.

Want to make a complaint?

If you would like to make a complaint about the study, please contact your local complaints service on (telephone number) or (email).

Thank you for reading this.

Contact details

We would be very happy to answer any questions you have, so please contact us if you have any queries:

We can also be contacted at the following address:

Research Department of Clinical, Educational and Health Psychology, Gower Street, WC1E 6BT

Appendix F

Young Person Consent Form

Patient Identification Number:



CONSENT FORM

Young Person

Title of Project: **How does staying in an adolescent unit impact on how adolescents view their future?**

Name of Researchers:

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 25/01/13 (version 1.0) for the above study.

2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my care being affected.

4. I understand that my participation in the study will be audio-taped and that what I say might be used as quotes in the write up of the study. I am aware that any quotes used will be anonymised. I give permission for this to happen.

5. I understand that other information will be collected during the study (age, gender, diagnosis, length of stay). I am aware that this information will remain confidential. I give permission for the researchers to have access to my information stated above.

6. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person Date Signature
taking consent

Appendix G

Parental Consent Form

Patient Identification Number:



CONSENT FORM

Parent/Carer

Title of Project: **How does staying in an adolescent unit impact on how adolescents view their future?**

Name of Researchers

Please initial all boxes

7. I confirm that I have read and understand the information sheet dated 06/02/13 (version 1.0) for the above study.
8. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
9. I understand that my son/daughter's participation is voluntary and that I am free to withdraw my son/daughter at any time without giving any reason, without their care being affected.
10. I understand that my son/daughter's participation in the study will be audio-taped and that what they say might be used as quotes in the write up of the study. I am aware that any quotes used will be anonymised. I give permission for this to happen.
11. I understand that other information about my son/daughter will be collected during the study (age, gender, diagnosis, length of stay). I am aware that this information will remain confidential. I give permission for the researchers to have access to my son/daughter's information stated above.
12. I give permission for my son/daughter to take part in the above study.

Name of Parent/Carer

Date

Signature

Name of Person

Date

Signature

taking consent

Appendix H

Semi-Structured Interview Schedule

Interview Schedule

General experience

- What has it been like staying here?
 - Prompt: The good/bad bits
- How is it different to your life at home?

Prior to admission

- What was going on in your life before coming here?
 - Prompt: How did you end up coming here?

Relationships

(Current relationships)

- What is it like living with lots of other young people?
- Is there anyone here you feel close to?
- How confident do you feel about meeting new people and making friends?

(Home friends)

- How are things with your home friends?
 - Prompt: Have you stayed in touch?
- How do you imagine things will be when you leave here?

(Family)

- How is your relationship with your family?
- Has this changed since being here?
- How do you imagine things will be when you leave here?

School

- What is the school like here?
- How is it different to your school at home?
- Have your ideas about education/study changed at all?

Independent living

- What is it like to look after yourself and do day to day tasks here?
- Have you been coping differently here to how you were coping at home?
- Has your confidence changed in how well you can cope with daily struggles in your life?
- How do you imagine you will cope with struggles when you leave here?
- Who else do you get/need support from? Has that changed?
- Are there certain things that you can't do on your own? Or need support with?

Stigma

- How do you feel about staying in a place for young people with emotional problems and difficulties with daily living?
- How would you feel about other people knowing you are/were here?

- Prompt: What do you imagine people would think if they knew?
- Prompt: Does it change how you see yourself in anyway?
- Do you think it has changed how things will be for you in the future? (e.g. your opportunities/chances)

Changes in self

- Do you see yourself any differently now? (before/after)
- Do you think others will see you differently?

Leaving hospital

- What are your biggest hopes/fears about leaving here?
- What do you imagine you will be doing shortly after leaving here? (e.g. weeks/months)? How about later down the line (e.g. years)?
- What will it be like living back at home? (e.g. without the things you have here)
- What support do you think you will need when you are discharged?
- How will you manage with the things that brought you here? (e.g. emotional problems)
- How do you imagine your life would be if you hadn't come here? What would you be doing instead?

Appendix I

Thematic Analysis Example

Extract	Initial notes	Coding	Theme (category)
I: Ok I guess kind of related to that, just to move on slightly because you've talked about the young people here, but do you feel... is there anyone here who you feel particularly close to, whether that's staff or young people?			
P: I mean pretty much all of the young people have a connection to in one way or another. Umm like I'm really close to (young person) I mean we're practically the same person (laughs). We've been through really similar stuff, physical and emotional [I: right ok] and so you automatically connect to that. (Fellow inpatient) I get on really, really well with. (fellow inpatient) she's like my sister, like she's only 14 bless her. I do kind of fit into that big sister and look out for her quite a bit, like when she's been naughty and stuff (laughs). But you do form a family, definitely form a family in this place.	<i>Have a connection to all the fellow inpatients</i>		
	<i>Been through similar experiences, makes you automatically connect</i>	<i>Strong connection with fellow inpatients due to shared experiences</i>	<i>A shared experience</i>
	<i>Form a family</i>	<i>Fellow inpatients are like siblings – like a family</i>	<i>“A substitute family”</i>
I: Yeah you said that towards the beginning, what... why do you use that word? What do you think it is about this place that makes it feel like a family?			
P: The fact that you live with each other day in and day out 24/7 [I: mm] that definitely makes it a family. The fact you sort of, I don't know, when you chuck a load of people together it either goes one way or another [I: yeah] you got to bond in order to make it work and everyone's really comforting coming in, and	<i>Live with young people 24/7</i>	<i>Intensive nature of the unit – people around 24/7</i>	<i>“I can always talk to someone”</i>
	<i>You have to bond in order to make it work</i> <i>Everyone is really comforting</i>	<i>Everyone is caring and supportive</i>	

as soon as someone new comes in your like
'hey how are you?' like...

I: And what do you think helps you to bond with
other people, what do you think it is about
being here that makes you bond?

P: It's similarities, like [I: in what way?]. well in
the outside world how many people do you
meet who knows what it's like to have a
flashback [I: mm]. and like, I mean really
knows what it's like to have a flashback. I
mean you can describe it until the cows have
gone home but you don't get it unless you've
had one. How many people really know what
it's like to be abused, like, [I: mm]. you don't
find that and like unless you've had
depression, personality disorders stuff like
that you don't know what it's like until
you've had that [I: mm]. knowing that there's
some... knowing that you're not the only one
and knowing that there's other people who are
going through the same thing automatically
makes you bond [I: mm], because you tend to
attach yourself to someone who knows what
you're going through especially if it's a
difficult thing. If it's a difficult thing and it's a
thing that not many people go through when
you do find those people who do get it you
automatically attach. And you automatically
have a lot more empathy and you feel for
them because you know what it's like because
you've been through it [I: right ok]. So when
they go through it you really, really feel for
them. Like you know, if someone else is

*People in the outside world
haven't had the same experiences
- don't know what it's like*

*People on the outside world don't
understand me*

*You don't know about mental
health problems until you've had
them*

*Shared experiences leads to better
understanding*

*Knowing that there's other
people going through the same
thing makes you bond*

*Shared experiences leads to
stronger connection*

*Automatically feel a lot more
empathy towards fellow
inpatients*

A shared experience

<p>having a flashback, I mean staff will have their professional head and deal with it how they deal with it, you know if any random person you saw it on the street they'd think 'oh ok' and then you find out that they're having flashback about a past event and then you're like 'oh that can't be good' [I: mm]. but when you've had it yourself you really, really feel for them and you really get upset, you know what I mean? That starts the emotional bond [I: right ok, so it's that collection of things that help you bond] yeah absolutely, you don't end up feeling like you're the only one.</p>	<p><i>Staff will have their professional head and deal with distress</i></p>	<p><i>Staff deal with problems as a professional – different support compared to fellow inpatients</i></p>	
<p>I: And is that how you felt prior to coming here?</p>	<p><i>When fellow inpatient is distressed makes you upset</i></p>	<p><i>Negative impact of seeing others distressed</i></p>	
<p>P: I did feel that no one really understood, like, [I: mm]. I mean I just felt, I do fell crazy. Of course deep down you do know that there must be other people out there, but when you've never met them [I: yeah] it gets harder and harder to convince yourself and like, I don't know, it's like... you know seeing things, seeing demons and stuff like that. I mean I know it's not normal, I know everyone doesn't going around seeing it so I don't tell people but you know what I mean? But it does make me feel crazy. Then to come in here and know that 'hold on a minute, we're either both crazy together or we're not that crazy'.</p>	<p><i>You don't end up feeling like you're the only one</i></p>	<p><i>Not alone – other people with problems</i></p>	
<p>P: I did feel that no one really understood, like, [I: mm]. I mean I just felt, I do fell crazy. Of course deep down you do know that there must be other people out there, but when you've never met them [I: yeah] it gets harder and harder to convince yourself and like, I don't know, it's like... you know seeing things, seeing demons and stuff like that. I mean I know it's not normal, I know everyone doesn't going around seeing it so I don't tell people but you know what I mean? But it does make me feel crazy. Then to come in here and know that 'hold on a minute, we're either both crazy together or we're not that crazy'.</p>	<p><i>Before felt like no one understood me</i></p>	<p><i>Before people didn't understand me</i></p>	<p><i>A shared experience</i></p>
<p>P: I did feel that no one really understood, like, [I: mm]. I mean I just felt, I do fell crazy. Of course deep down you do know that there must be other people out there, but when you've never met them [I: yeah] it gets harder and harder to convince yourself and like, I don't know, it's like... you know seeing things, seeing demons and stuff like that. I mean I know it's not normal, I know everyone doesn't going around seeing it so I don't tell people but you know what I mean? But it does make me feel crazy. Then to come in here and know that 'hold on a minute, we're either both crazy together or we're not that crazy'.</p>	<p><i>Meeting fellow inpatients makes me not feel as crazy</i></p>	<p><i>Comfort in meeting fellow inpatients – not alone</i></p>	