

VOLUME I

RESEARCH COMPONENT

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A thesis submitted to the University of Birmingham as partial
fulfilment of the registration for the degree of Doctorate in Clinical
Psychology.

Doctoral Degree in Clinical Psychology

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Overview

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (D.Clin.Psy.) at the School of Psychology, University of Birmingham, UK. It comprises two volumes. Volume I consists of the research component whilst Volume II comprises the written clinical component based on work completed during training.

Volume I comprises of a systematic literature review, an empirical research paper and a public domain paper. The systematic literature review considers available literature investigating mental health literacy and help-seeking behaviours in young people. The empirical research paper explores young people's experiences who upon reaching the upper age limit for Child Adolescent Mental Health Services (CAMHS) are discharged rather than being transferred into Adult Mental Health Services (AMHS).

Volume II contains five Clinical Practice Reports (CPR's). CPR1 presents both cognitive behavioural and systemic formulations of a 16 year old female referred to CAMHS due to symptoms of depression. CPR2 is a service evaluation which aimed to assess service users' perspectives of the Choice And Partnership Approach (CAPA), a newly implemented way of working within CAMHS. CPR3 presents a case-study of a 67 year old man, referred to mental health services for older people, due to long-standing symptoms of depression. CPR4 documents a single-case experimental design that

assessed the effectiveness of a behavioural intervention implemented to reduce symptoms of Obsessive Compulsive Disorder (OCD) in a 13 year old male with a moderate learning disability. An abstract outlining CPR5, a clinical presentation about a 21 year old female referred to a systemic service following developing symptoms of depression related to difficult family relationships is also included.

Contents of volume I

| | Page |
|-------------------------------------|------|
| Systematic literature Review | 1 |
| Abstract | 2 |
| Introduction | 3 |
| Methodology | 5 |
| Results | 32 |
| Discussion | 51 |
| References | 58 |
| | |

| Empirical Paper | Page number |
|---|-------------|
| What are the experiences of young people who following their discharge from Child and Adolescent Mental Health Services (CAMHS) do not transfer into Adult Mental Health Services (AMHS)? | 65 |
| Abstract | 66 |
| Introduction | 67 |
| Method | 71 |

| | |
|--|-----|
| Results | 78 |
| Discussion | 96 |
| References | 107 |
| Public domain briefing paper | 112 |
| Appendix 1 : Participant opt in letter | 116 |
| Appendix 2 : Participant information sheet | 118 |
| Appendix 3 : Consent form | 123 |
| Appendix 4 : Interview Schedule | 126 |
| Appendix 5: Reflexive account | 130 |
| Appendix 6 : Notes to contributors to The Journal of Child Psychology and Psychiatry | 132 |

List of figures:

| Literature review | |
|---|-------------|
| Name of figure | Page number |
| Figure 1: Flow-chart demonstrating systematic search for relevant studies | 9 |

List of tables literature review:

| Literature review | |
|---|--------------------|
| Name of table | Page number |
| Table 1: Summary of non-intervention studies | 10 |
| Table 2: Summary of intervention studies | 22 |
| Table 3: Quality review of non-intervention studies | 26 |
| Table 4: Quality review of intervention studies | 29 |

List of tables Empirical paper:

| Empirical paper | |
|--|--------------------|
| Name of table | Page number |
| Table 1: Summary of non-intervention studies | 75 |
| Table 2: Summary of intervention studies | 78 |

Contents of Volume II

| | Page |
|--|------|
| CPR 1: Psychological Models | |
| Title: A 16 year old female with depression referred to child and adolescent mental health services (CAMHS). Formulation of presenting difficulties from cognitive behavioural and systemic perspectives. | 1 |
| Abstract | 2 |
| Assessment | 3 |
| Cognitive Behavioural Formulation | 9 |
| Systemic Formulation | 19 |
| Critical appraisal | 27 |
| References | 29 |
| | |
| CPR 2: Service evaluation: Small scale service related research project | |
| Title: Evaluation of service users satisfaction with Choice and Partnership Approach (CAPA) | 32 |
| Abstract | 33 |
| Introduction | 35 |

| | |
|---|----|
| Aims of the service evaluation | 41 |
| Methodology | 42 |
| Qualitative results | 45 |
| Quantitative results | 53 |
| Discussion | 58 |
| References | 65 |
| Appendix 1 : CHI-ESQ for young people | 68 |
| Appendix 2 : CHI-ESQ for parents and carers | 70 |
| Appendix 3 : Information sheet- retrospective postal recruitment | 72 |
| Appendix 4 : Information sheet- post appointment | 74 |
| Appendix 5 : Consent form | 76 |
| Appendix 6 : Confidential appendix (parents and carers) | 77 |
| Appendix 7 : Confidential appendix (young people) | 82 |
| | |
| CPR3 : Case Study | |
| The case study of a 67 year old man with depressive symptoms | 84 |
| Abstract | 85 |

| | |
|--|-----|
| Case summary and assessment | 86 |
| Formulation | 93 |
| Intervention | 97 |
| Evaluation | 104 |
| Reflections | 106 |
| References | 108 |
| Appendix 1: Thoughts, feelings, behaviour maintenance cycle for depression | 111 |
| Appendix 2: Thoughts, feelings, behaviour diary | 112 |
| | |
| CPR4: Single Case Experimental Design | |
| Title: The case of a 13 year old boy referred into a learning disability service for treatment of obsessive compulsive symptoms | 113 |
| Abstract | 114 |
| Assessment | 115 |
| Formulation | 122 |
| Intervention | 126 |

| | |
|---|-----|
| Experimental Design | 129 |
| Data Analysis | 131 |
| Discussion | 134 |
| References | 139 |
| | |
| CPR 5: Oral presentation | |
| Title: Case study of a 21 year old female referred to a systemic psychological therapies services due to symptoms of depression. | 143 |

List of figures.

| CPR1: Psychological Models | |
|--|--------------------|
| Name of figure | Page number |
| Figure 1: Cognitive behavioural formulation of Amy's depression and school avoidance | 13 |
| Figure 2: CBT maintenance cycle | 15 |
| Figure 3: Multiple levels of context | 24 |

| |
|--|
| CPR4: Single Case Experimental Design |
|--|

| Name of figure | Page number |
|--|--------------------|
| Figure 1: Formulation of Jack's difficulties | 122 |
| Figure 2: Maintenance cycle of Jack's difficulties | 126 |
| Figure 3: Graph to show frequency of hand-washing across baseline and Intervention phases | 131 |
| CPR3: Case Study | |
| Name of figure | Page number |
| Figure 1: Example of situation, thought, feeling, behaviour diary | 90 |
| Figure 2: Cognitive behavioural formulation of depression | 95 |

List of tables:

| CPR2: Service evaluation- Small scale service related research project | |
|--|--------------------|
| Name of table | Page number |
| Table 1: The 4 tiered system of CAMHS in the UK | 36 |
| Table 2: The 5 key outcomes of Every Child Matters | 37 |
| Table 3: Referral data to specialist CAMHS | 46 |
| Table 4: Specific Choice appointment data | 46 |
| Table 5: Results of parent responses for CHI-ESQ | 49 |
| Table 6: Results of young people responses for CHI-ESQ | 50 |
| Table 7: Satisfaction scores for adults and young people within the West Midland CAMHS and East Herts CAMHS | 51 |

LITERATURE REVIEW

MENTAL HEALTH LITERACY AND HELP SEEKING BEHAVIOUR IN YOUNG PEOPLE: A REVIEW OF THE LITERATURE.

Abstract

It has been suggested that help-seeking behaviours in young people experiencing mental health difficulties may be moderated by a number of factors. This includes their knowledge and beliefs about mental health difficulties (mental health literacy) and how to access appropriate sources of formal or informal support. The aim of this paper was to review the available literature on mental health literacy and help-seeking behaviour in young people.

Sixteen articles were identified for review. They were split into two groups, non-intervention and intervention studies. All articles were subjected to the rigours of quality assurance ratings to enable the reliability and validity of the findings to be assessed.

General findings for non-intervention studies identified certain sub-groups of young people (i.e. being female and older in age) as having better mental health literacy and knowledge regarding where to seek help. Intervention studies reported mixed findings in terms of increasing mental health literacy and help-seeking through educational methods.

Limitations of the studies are discussed, followed by a discussion regarding clinical implications of the findings and areas for future research.

Keywords: Mental health literacy; help-seeking behaviour; young people; mental health difficulties.

Introduction

“Help-seeking” for mental health difficulties has been defined as an individual actively recognising that they have a problem and seeking support from either formal sources of help (e.g. GP, counsellor, psychologist) or informal sources (e.g. family, friends). Successful help-seeking relies upon an individual being able to recognise difficulties within themselves, being able to verbalise the problems to others, and having an awareness and belief in the effectiveness of treatment options available to them (e.g. Rickwood, Deane, Wilson & Ciarrochi, 2005).

Young people are more likely to seek help from informal sources than from formal help sources (Reavley, Yap, Wright & Jorm, 2011; Sheffield, Fiorenza & Sofronoff, 2004). They are therefore also likely to act as informal support for peers in their social groups (Jorm, 2000). However, a recent study found that young people were unlikely to encourage peers to seek help from professionals as they lacked knowledge of appropriate local support agencies and were unsure what mental health professionals could offer (Yap, Reavley & Jorm, 2012). Targeted mental health promotion focusing on education to improve knowledge about mental health, appropriate interventions, and how to support others with mental health difficulties has been identified as being required (e.g. Jorm, Wright & Morgan, 2007).

Mental health promotion for young people is also especially relevant considering development of the first episode of mental health difficulties such as depression has been found to peak in the period between late adolescence and into early adulthood (Kessler et al, 2005; McGorry, Purcell, Goldstone & Amminger, 2011). Epidemiological research has indicated that more than half of all adults with mental health difficulties had their first episode in childhood or adolescence (Kessler et al, 2007; Hofstra, Van der Ende & Verhulst, 2002; Copeland, Shanahan, Costello & Angold, 2009; Kim-Cohen et al, 2003; Jonsson et al, 2011). Enabling young people to identify and obtain treatment for mental health difficulties when they first occur could reduce the number of young people moving into adulthood with mental health difficulties, thus leading to improved future social, occupational and personal outcomes (McGorry, Purcell, Hickie & Jorm, 2007; Rickwood et al, 2005; Vander Stoep, Beresford, Weiss, McKnight, Cauce & Cohen, 2000). However, it has been demonstrated that young people may not recognise that they have mental health difficulties or that mental health professionals may be a useful source of support (Vanheusden et al, 2008).

Even if difficulties are recognised, a number of potential barriers prevent young people seeking help for mental health difficulties. For example, Biddle, Donovan, Gunnell & Sharp (2006) and Leavey, Rothi & Paul (2011) found that young people did not realise that they could approach their GP for support with mental health difficulties. This suggests that young people are not aware of whom to approach for help. Furthermore, stigma or embarrassment about having a mental health difficulty and attitudes and

beliefs about services and treatments have also been suggested as potentially influencing whether young people actively seek help from formal support networks (Gulliver, Griffiths & Christensen, 2010; Wilson, Deane & Ciarrochi, 2005; Jorm et al, 2003).

Studies have suggested that mental health literacy within the general population is low (Jorm, 2000), which reduces the plans or choices which a person can make about how best to access help (Lauber, Nordt, Falcato & Rossler, 2003).

Methodology

The aim of this paper was to review empirical papers which specifically investigated the relationship between mental health literacy and help-seeking behaviours in young people. To do this, a systematic review was completed. Systematic reviews aim to identify, review and evaluate the available literature to enable future policies and guidelines to be devised and implemented. Subjecting the literature to such evaluation procedures also enables any gaps in the literature to be identified so they can subsequently be addressed in future research projects.

To conduct this systematic literature review, a standard protocol was followed (Centre for Research Dissemination, 2008). An initial search of the topic area was conducted to

investigate what literature was available, i.e. mental health literacy and help seeking behaviour. This enabled key search terms used by electronic databases to be identified. These key search terms were used to develop a robust search strategy for use within relevant electronic databases (please refer to Flow-chart 1 for search strategy). Inclusion and exclusion criteria were also defined. Inclusion criteria included:

- Males or females, aged 12-25 years.
- Research must specifically measure mental health literacy and help-seeking behaviour including intervention as well as non-intervention studies.

Exclusion criteria included:

- Papers which exclusively recruited participants over the age of 25 years.
- Papers which were not written in English due to problems with translation.
- Non-empirical papers.

The key search terms and inclusion/ exclusion criteria were entered into electronic databases to identify relevant journal articles. The following databases were used to identify papers to be included in the review: Psycinfo (1987-2012); Medline (1988-2012); Web of Knowledge. These databases were chosen to enable a broad search of the literature to be conducted. For example, Web of Knowledge covered education alongside social sciences therefore identifying any papers concerning mental health

literacy and help-seeking behaviour in educational settings, which was important due to the age range specified in the inclusion criteria.

Following a search of the electronic databases the abstracts of the identified articles were reviewed enabling inclusion of those which were relevant to the question being asked, and those which did not to be excluded. Following identification of relevant articles to be included in the literature review, a manual search of their reference lists was conducted to identify any papers which may have been missed following the keyword search of the electronic database. Conducting a stringent search of the literature is a key aspect of a systematic literature review. This search procedure increases the reliability of the review as it ensures relevant papers are not excluded.

A further important phase of a systematic literature review is assessing the quality of the articles identified. Quality grids are used to review various aspects of the papers including strength and suitability of methodology and statistical procedures utilised, and generalisability of results to the general population.

Following identification, the papers were split into two categories, namely intervention studies and non-intervention studies. Each of the papers was subsequently reviewed (a summary of their aims, methodology, and results is provided in tables 1 and 2). A quality assurance rating grid was subsequently completed (modified from American

Academy of Neurology Clinical Practice Guidelines, 2004; and is presented in tables 3 and 4). This was to enable scrutiny of the conceptual basis, research design and methodology, suitability of measures used to measure the variables in question, and data analysis procedure to enable evaluation of the conclusions drawn. Each item on the quality assurance rating grid was rated 0-2. A score of 0 indicated no evidence that the criteria had been met; a score of 1 indicated that there was some evidence that the author(s) had met the criteria; and a score of 2 indicated that there was definite evidence that the author(s) had met the criteria.

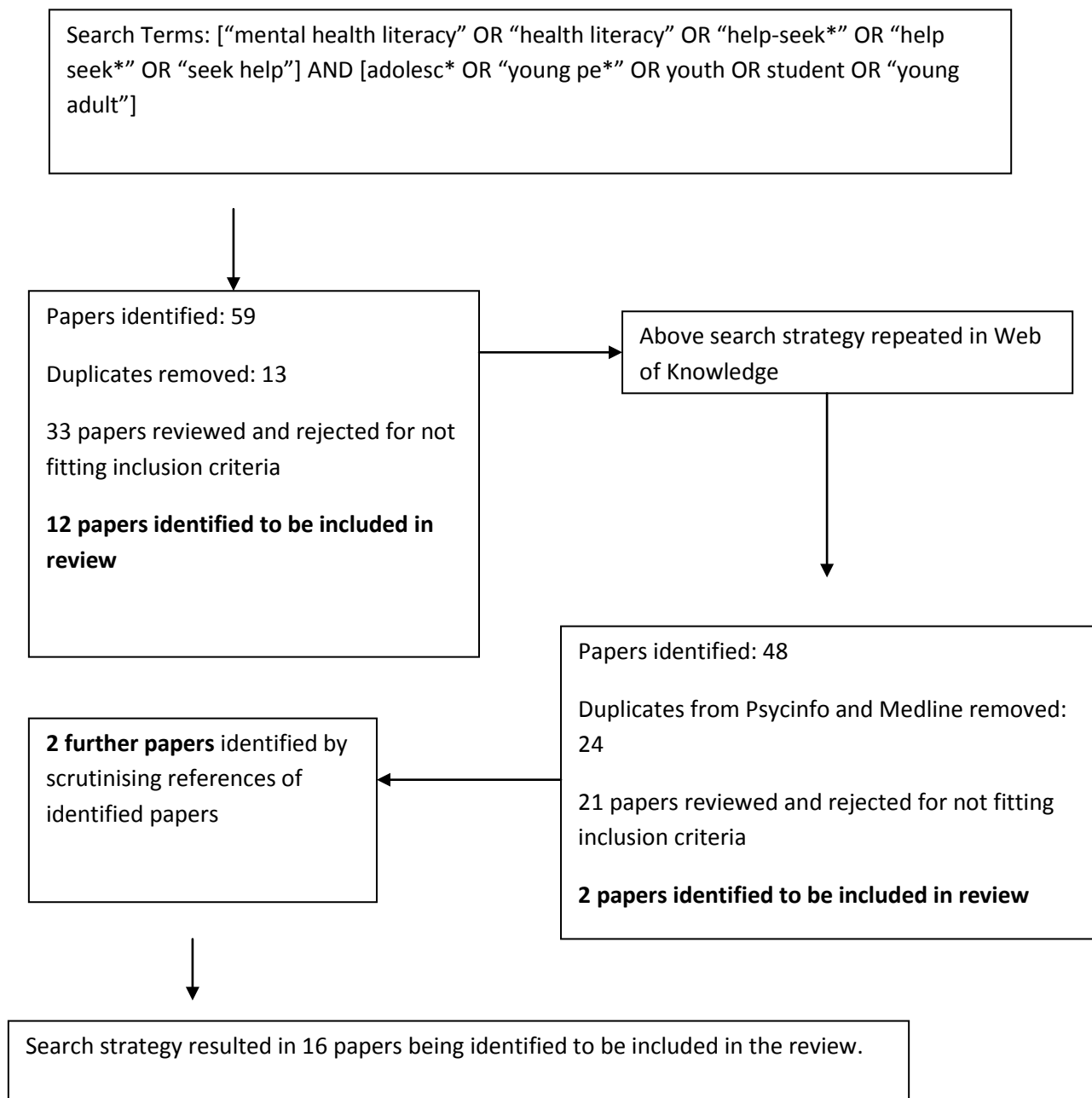


Figure 1: Flow chart demonstrating search for relevant studies.

Table 1: summary of non-intervention studies looking at mental health literacy and help-seeking behaviour in young people.

| Study (Country of origin) | Aims | Participants | Methodology (including measures) | Results |
|---|---|--|--|---|
| <p>Burns & Rapee (2006)</p> <p>Australia</p> | Investigated mental health literacy with regards to depression and help seeking recommendations in adolescents. | 202 adolescents aged 15-17 years (60% males) | <p>Vignette based questionnaire designed for this study. Participants predominantly required to self-generate answers to questions.</p> <p>Participants required to self-generate labels for problems outlined in 5 vignettes (2 depicting depression, 3 depicting general life stresses); identify symptoms indicative of depression; rate level of concern for character (Likert scale, 1-5); indicate perceived recovery time; indicate whether help would be required to overcome difficulties, and Indicate where to seek help.</p> | <p>Depression identified most successfully in character with most severe symptoms.</p> <p>Females significantly more likely to correctly label vignettes as depressed ($p<0.05$).</p> <p>Vignette characters depicting depression more likely to be identified as depressed than in other vignettes.</p> <p>Concern for character in vignettes: main effects for vignettes outlining depression ($p<0.05$) and gender of respondents being female ($p<0.05$).</p> <p>Help recommended for depressed character (males: females):</p> <p>Counsellor (46%: 75%,$p<0.05$), friends (40%: 44%, ns), family (41%: 41%, ns).</p> <p>Doctor recommended least often (1%: 2%).</p> |

| Study Country of origin | Aims | Participants | Methodology (including measures) | Results |
|---|---|--|--|--|
| Chen, Mond, & Kumar, (2010) Singapore | To measure mental health literacy with respect to bulimia nervosa (BN); and beliefs about treatment in women. | 255 women, mean age 19 years (SD, 1.8 years). Undergraduate students (1 st year psychology students; and 1 st or 2 nd year business and engineering students). | Mental health literacy survey (Jorm et al, 1997) modified to depict a female character with BN symptomatology. Participants choose the label they thought was most representative of difficulties presented. Participants rated helpfulness of interventions listed (helpful, harmful, or neither). Indicate who they would approach if they experienced similar difficulties. Indicate whether they thought the condition was treatable. Eating Disorder Examination Questionnaire (EDE-Q, Fairburn & Beglin, 1994) assessed eating disorder psychopathology in participants. The association between levels of eating disorder psychopathology and responses regarding vignette assessed. | Labelling disorder: participants modal response was low self esteem (38%), followed by BN (14.5%), anorexia nervosa (14.1%). Most helpful formal sources of support: dieticians (19.5%); counsellor (18.3%). Informal sources of support: close friend (11.2%); mother (9.6%). Medications: vitamins and minerals (66.9%); antidepressants (16.9%). Those who identified problem as BN were significantly less likely to rate advice from gym instructor as helpful; and rated taking advice on weight loss as harmful. Prognosis: modal response was that there would be recovery, but relapse was likely. 12% of participants (N=31) identified as having symptoms consistent with eating disorder psychopathology. Responses showed they were significantly more likely to rate gym instructors as helpful, and professionals such as counsellors and psychiatrists as being unhelpful. |

| Study (country of origin) | Aims | Participants | Methodology (including measures) | Results |
|--|--|--|---|--|
| Coles, & Coleman (2010) USA | To investigate mental health literacy for anxiety disorders. | 284 undergraduate psychology students (59% female). Mean age 19 years. | Mental Health Literacy Questionnaire for Anxiety Disorders (MHL-AD; modified from Jorm et al, 1997). Depicted common anxiety disorders: Generalised Anxiety Disorder (GAD), Obsessive Compulsive Disorder (OCD), social phobia, panic disorder. Vignette depicting depression was also included for purposes of comparison. For each vignette, participants were required to label the disorder depicted; the treatment options available and rate effectiveness of treatments; and cause of symptoms. | Social phobia and OCD had best recognition rates (4 out 5 participants correctly identified disorders). Females significantly more likely than males ($P<0.05$) to correctly identify GAD and social phobia. Recognition better if participant knew someone who had experienced the disorder. Professional help most likely to be recommended for panic disorder and OCD. Participants attributing cause to mental illness or biological causes increased the likelihood of recommending professional help. |

| Study Country of origin | Aims | Participants | Methodology (including measures) | Results |
|---|--|--|--|---|
| Wright, Harris, Wiggers, Jorm, Cotton, Harrigan, Hurworth & McGorry, (2005) Australia | To assess young people's ability to recognise depression and psychosis; and to ascertain beliefs about sources of support. | 1207 young people (aged 12-25). Stratification via age groups (12-17; 18-25years). 539 males (45%), 668 female (55%). 606 participants received depression vignette. 601 received psychosis vignette | Cross-sectional telephone survey using Mental Health Literacy questionnaire (adapted from Jorm et al, 1997). 4 vignettes developed: 2 depicting symptoms of depression (1 male, 1 female character); 2 depicting symptoms of psychosis (1 female, 1 male character). Vignettes randomly assigned to participants so to counterbalance presenting difficulty and gender of vignette character. 17 minute telephone survey conducted. Investigated the association between accurate labelling of depression and psychosis with participants knowledge of appropriate treatment/ sources of support and participations views regarding prognosis of presenting difficulty. | Depression correctly identified significantly more frequently than psychosis across both age groups ($p<0.001$). Older participants were significantly more likely to identify both depression and psychosis. Older participants were more likely to identify suitable forms of formal and informal support for the character depicting depression. A higher percentage of participants (59%) who correctly labelled depression were able to identify an appropriate source of help compared to those young people who were unable to label the disorder (47%). Similar findings were reported for the psychosis vignette, with 75% of those correctly labelling the disorder suggesting appropriate help, compared to 59% of those unable to label the disorder. Rating interventions resulted in over 70% of participants choosing all of the listed sources as being helpful. |

| Study (country of origin) | Aims | Participants | Methodology (including measures) | Results |
|--------------------------------------|--|--|---|---|
| Smith (2011) Australia | <p>Pilot study looking specifically at the relationship between mental health literacy and help-seeking behaviours in young people.</p> <p>To determine which domains of mental health literacy best predict help seeking behaviour.</p> | <p>150 University Students (aged 17-26 years).</p> <p>Females- 78.7% (N=118)</p> | <p>Modification of Jorm et al's (1997) Mental Health Literacy Survey. 2 vignettes devised 1 depicting social anxiety, 1 depicting depression. Participants required to label presenting difficulty; and to choose appropriate sources of support from a list provided.</p> <p>Completion of the General Help Seeking Questionnaire (GHSQ, Rickwood et al, 2005) enabled scores regarding participants intentions to seek help from formal and informal sources of support to be ascertained.</p> <p>A question regarding confidentiality was included in the questionnaire to ascertain the impact of this on attitudes towards help seeking.</p> | <p>Data was analysed using multiple regression. The components of mental health literacy found to be most predictive of help seeking behaviour were: participants beliefs about mental illness ($p<0.05$); participants beliefs about confidentiality of sessions ($p<0.05$); participants knowledge regarding appropriate interventions ($p<0.01$); and affordability of health care ($p<0.01$).</p> |

| Study Country of origin | Aims | Participants | Methodology (including measures) | Results |
|---|--|---|--|---|
| Wright, Jorm, Harris & McGorry (2007) Australia | To assess young people's ability to recognise depression and psychosis; and to ascertain beliefs about sources of support. | 1207 young people (aged 12-25). Stratification via age groups (12-17; 18-25years). 539 males, 668 female. 606 participants- received depression vignette. 601 received psychosis vignette | Cross sectional telephone survey using Mental health literacy questionnaire (adapted from Jorm et al, 1997). 4 vignettes developed: 2 depicting symptoms of depression (1 male, 1 female character); 2 depicting symptoms of psychosis (1 female, 1 male character) Vignettes randomly assigned to participants so to counterbalance presenting difficulty and gender of vignette character. 17 minute telephone survey conducted. Interaction between correct labelling of disorder and participants identifying suitable sources of support investigated. | Correct identification of the disorder was the best predictor of appropriate sources of help being identified by the participants. Overall, participants were less able to identify psychosis. This reduced their ability to be able to identify appropriate sources of support. Being older in age and female was also associated with increased ability to identify appropriate sources of help for the disorders depicted. Having a family member or friend who had experienced depression was also associated with increased rates of identifying certain appropriate sources of help such as GP, or counsellor. Participants who had experienced similar symptoms to depression vignette were more likely to recommend sources of support such as antidepressants, and social workers. Younger participants were more likely to recommend inappropriate help such as alcohol, and marijuana. |

| Study Country of origin | Aims | Participants | Methodology (including measures) | Results |
|--|--|---|--|--|
| <p>Cotton, Wright, Harris, Jorm & McGorry (2006).</p> <p>Australia.</p> | <p>To investigate gender and age related differences in mental health literacy for depression and psychosis identification and help seeking recommendations.</p> | <p>1207 young people (aged 12-25).</p> <p>Stratification via age groups (12-17; 18-25years).</p> <p>539 males, 668 female.</p> <p>606 participants- received depression vignette.</p> <p>601 received psychosis vignette.</p> | <p>Cross-sectional telephone survey using Mental Health Literacy questionnaire (adapted from Jorm et al, 1997).</p> <p>4 vignettes developed: 2 depicting symptoms of depression (1 male, 1 female character); 2 depicting symptoms of psychosis (1 female, 1 male character)</p> <p>Vignettes randomly assigned to participants so to counterbalance presenting difficulty and gender of vignette character. 17 minute telephone survey conducted.</p> <p>Participants required to: self generate a label for the disorder; recommend treatment options; answer questions regarding helpfulness of a list treatments for their particular vignette.</p> | <p>Males and females significantly more likely to identify depression than psychosis ($p<0.05$). Females significantly more likely to correctly identify depression than males regardless of age group ($p<0.01$). No gender differences found for accurately labelling psychosis.</p> <p>Vignette character gender: recognition of depression significantly greater for male character; no gender differences for identification of psychosis.</p> <p>No significant differences between males and female responses in terms of recommended sources of support for either depression/ psychosis.</p> <p>Recommended support for both depression and psychosis: family/ friends; followed by seeing a counsellor/ psychologist.</p> <p>Medications recommended for depression: vitamins, minerals; for psychosis: antidepressants.</p> |

| Study Country of origin | Aims | Participants | Methodology (including measures) | Results |
|--|--|---|---|---|
| <p>Mond, Marks, Hay, Rodgers, Kelly, Owen, & Paxton, (2007).</p> <p>Australia</p> | <p>Investigate bulimia nervosa (BN) related mental health literacy and help seeking behaviour in a sample of female adolescents.</p> | <p>522 female secondary school students (12-18years).</p> | <p>Opportunity sample.</p> <p>Mental health literacy survey (Jorm et al, 1997) modified to depict a character with symptomatology consistent with BN.</p> <p>All participants completed Eating Disorder Examination questionnaire (EDE-Q; Fairburn & Beglin, 1994) to measure eating disorder psychopathology in the sample.</p> <p>Participants required to label difficulty; rate sources of support (helpful, harmful or, neither helpful nor harmful to character); and to indicate whether they believed BN was treatable.</p> | <p>Sources of informal support recommended for the character was most frequently mothers (19.4%). Formal sources of support: dietician/nutritionist (18.5%). Intervention most frequently chosen as being helpful was CBT (26.3%). Vitamins/ minerals seen as medication most likely to be helpful (60.2%).</p> <p>Participants identified that if they were experiencing similar difficulties they would most likely approach their mother (37%); followed by female friend (33.7%).</p> <p>82.2% indicated they believed character's difficulties would worsen with no treatment. 40.5%- believed problems would re-occur despite treatment.</p> <p>6.9% (N=36) of participants met criteria for likely BN psychopathology (EDE-Q). They were significantly less likely to identify BN ($p<0.05$); significantly less likely ($p<0.05$) to consider family and counsellors as being helpful sources of support.</p> |

| Study Country of origin | Aims | Participants | Methodology (including measures) | Results |
|--|--|--|--|---|
| Reavley, McCann, & Jorm, (2012 a). Australia | To investigate levels of mental health literacy for depression and associated help seeking behaviour, particularly in relation to identifying symptoms in others and how they had helped them. | 774 students (mean age 24.5; SD 8.4) 422 staff used as a control group (mean age 44 years; SD 11.2) 60% of participants were female. | Opportunity sampling. Recruitment through advertisements/ emails. Telephone interviews conducted with both groups of participants. Mental health literacy survey (Jorm et al, 1997) used. Participants required to: label characters difficulty; indicate whether they themselves had experienced similar difficulties; if they had, what actions they had taken to deal with the difficulties i.e. sources of support utilised. Participants also asked if they had, or knew anyone who had experienced similar difficulties and the support they had received or suggested. | 27% of students and 34% of staff reported they had experienced difficulties similar to the vignette character. 47% of these students and 45% of these staff correctly labelled vignette symptoms as depression. Staff significantly more likely ($p<0.05$) to seek help than students. Both students and staff identified close friends and family as being primary sources of support. Listening to the person came top for both students and staff followed by seeking professional help. Staff were significantly more likely than students to recommend seeking professional help ($p<0.05$). Factors associated with help-seeking behaviour: being born in Australia, being older in age and being female. |

| Study Country of origin | Aims | Participants | Methodology (including measures) | Results |
|--|--|---|---|--|
| Reavley, McCann, & Jorm (2012, b) Australia | Measure mental health literacy and help-seeking beliefs in students to inform future mental health promotion programmes. | N=774; students (mean age 24 years; 60% female) Control group N= 422: university staff (mean age 44years) | Opportunity sampling. Recruitment through advertisements/ emails. Telephone interviews conducted with both groups of participants. Mental health literacy survey (Jorm et al, 1997) used. Participants required to: label symptomatology (e.g. depression); indicate sources of appropriate support; rate beliefs about helpfulness of interventions. | 83% of students said that they would seek help if experiencing symptoms similar to those depicted in the vignette. GP's identified as being most likely source of formal support for both students (26%) and staff (50%). Most likely source of informal support for students was from friends (25%). In students, interaction effects for help seeking from professionals and being female ($p<0.05$). Being female, born in Australia, older in age, and with higher levels of education associated with correct labelling of depression. |

| Study Country of origin | Aims | Participants | Methodology (including measures) | Results |
|---|---|---|--|--|
| Stansbury, Wimsatt, Simpson, Martin, & Nelson (2011) USA | To investigate depression related mental health literacy and help seeking in African American College Students. | 54 African American students. Age range 18-24 years. 70% females (N=38). Recruited through University societies for African American students. | The Mental Health Literacy Survey (Jorm et al, 2000). 2 vignettes, one depicting a male and one a female character with symptoms of depression presented. Characters renamed to be culturally sensitive. Respondents required to: label depression; rate beliefs regarding prognosis (will recover; will recover with help; will not recover); to rate sources of support (as helpful, neither helpful or harmful; or harmful); to indicate whether they were aware of local sources of support for people with similar difficulties in their community. | Only descriptive datum was reported. 63% (N=34) participants correctly identified depression. From these, 84% indicated that recovery was possible with professional help. Without professional help, 35%- saw no chance of recovery; 41% saw little chance of recovery. 41% rated professional help such as psychologist, counsellor or doctor to be the best forms of support; 23% believed informal support (e.g. friends/ family members) would be preferable. Of those not identifying depression, 35% indicated professional help would be preferable; 5% informal support only. 89% of the sample reported that they knew about how to access information about mental health difficulties- mostly informal e.g. self help material. |

| Study Country of origin | Aims | Participants | Methodology (including measures) | Results |
|---|--|---|---|--|
| Swords, Hennessy, & Heary, (2011). Ireland. | To investigate whether being able to identify and label depression was associated with help-seeking behaviour. | 393 participants (males, N= 206; females N= 187) aged 12-19. Participants split into groups based upon age. Mean ages of groups: 12 (N= 107), 14 (N= 153), 16 (N= 153). | Cross sectional survey. 2 vignettes presented to participants one depicting symptoms of depression and one Attention Deficit Hyperactivity Disorder (ADHD). Gender of character counterbalanced across participants. A comparison vignette outlining an everyday situation (e.g. arguing with a friend causing upset) also included. Participants were asked to rate whether the character needed help (4 point scale) and who they should seek help from. | All age groups rated clinical vignettes as requiring more help than control vignette. 12 and 14year olds: significant differences for responses between ADHD and depression, with both indicating ADHD required more help. 16 year olds: no significant difference between help required for ADHD and depression vignettes. Sources of help: significant difference between 16year olds and other age groups, with 16 year olds suggesting significantly more sources of support regardless of vignette. All groups suggested more sources of support for ADHD than depression. In all 3 age groups family friends and school teachers rated as important sources of support. Mental health professionals more likely to be recommended for depression by 16 year olds than other age groups. Doctors rated as lowest for all age groups for both clinical conditions. |

Table 2: summary of intervention studies.

| Study (country of origin) | Aims | Participants | Methodology | Results |
|---|--|------------------------------------|---|--|
| <p>Robinson, Gook, Yuen, Hughes, Dodd, Bapat, Schwass, McGorry, & Yung, (2010).</p> <p>Australia</p> | <p>School based programme designed to increase mental health literacy and help-seeking behaviour for depression.</p> | <p>N= 246, 14-16year old boys.</p> | <p>Pre-test, post-test design with a wait list control group.</p> <p>2 hour workshop, delivering information regarding depression and formal/ informal sources of help. Information pack to take away.</p> <p>Vignettes based upon the Mental Health Literacy Survey (Jorm et al, 1997) were used to measure participants ability to label depression (participants chose responses from list provided). Participants were asked to indicate appropriate sources of support (list of options provided).</p> <p>Measures completed at three time points (time 1: baseline; time 2: following group 1 receiving intervention; time 3 following both groups receiving intervention).</p> | <p>Time point 2: no differences in recognition of depression between control and intervention groups. However, the intervention group were significantly more likely to indicate that they would seek help ($p<0.05$); intervention group were significantly more likely to choose professional support as being appropriate.</p> <p>Post intervention, there were no differences between groups in terms of recognition of depression. Both groups showed a significant increase in percentage of participants reporting they would seek help ($p<0.05$); of rating relevant professionals as helpful ($p<0.05$); Improved attitudes towards help-seeking ($p<0.05$).</p> |

| Study (country of origin) | Aims | Participants | Methodology (including measures) | Results |
|--|---|--|---|--|
| Costin, Mackinnon, Griffiths, Batterham, Bennett, Bennett, & Christensen (2009). Australia | Primary outcome: changes in help seeking behaviour. Secondary outcomes: changes in mental health literacy, including recognition of depression, attitudes towards treatment and the help seeking process. | Participants (N= 348) aged 19-24years. | Randomised Controlled Trial. Participants randomly assigned to intervention or control condition, based upon allocation to high or low psychological distress groups (distress measured using Kessler Distress Inventory; Andrews & Slade, 2001) and gender. Actual Help Seeking Questionnaire (AHSQ, Rickwood, Deane, Wilson, Ciarrochi, 2005) used to measure help seeking behaviour (pre and post intervention period). Internet based intervention. Over a 3 week period, participants received 3 personalised emails linking to a web-page (Health e-cards). Intervention condition: web- page contained information regarding depression and sources of support. Control condition: web-page contained information related to general health issues. Follow up at 3weeks post intervention to measure whether participants had sought help for mental health difficulties. Participant adherence to accessing web-sites following receiving e-mail was tracked. | No significant differences were found between the control and intervention groups for improving mental health literacy for depression (i.e. knowledge, beliefs, symptomatology). There were also no differences between groups for knowledge regarding appropriate forms of help seeking for depression. The only positive difference was that responses from participants in both control and intervention groups regarding seeking support from professional sources were more favourable post intervention period. |

| Study. (country of origin) | Aims | Participants | Methodology (including measures) | Results |
|--|---|--|---|---|
| Santor, Poulin, LeBlanc, & Kusumakar, (2007) Australia | Increase mental health literacy and subsequent <i>actual</i> help seeking behaviour for mental health difficulties. | Intervention group, N= 388. (school year 8) Control group, N= 738 (school years 7 & 9). 51% female across entire sample. | Non-randomised controlled trial. Intervention group: received 2 workshops over 8 month period (each of 1 hour duration) presenting information regarding mental health difficulties and help seeking. Intervention group also had access to web-site containing information regarding mental health difficulties and help seeking options. Control group: No intervention Outcomes: Monitored number and frequency of visits (including reasons for visits) to school based health centres for participants in both control and intervention groups. Participants in both conditions completed Beck Depression Inventory (BDI; Beck, Steer & Brown, 1997) and The Problem Duration Checklist (developed for this study) at the end of the school years to assess levels of psychopathology. | Main effect for intervention on attending school health centre for: total number of student visits ($p<0.001$); mental health visits ($p<0.05$); emotional support visits ($p<0.05$). Females within intervention group attended school health centre significantly more than males for: total number of visits ($p<0.05$) and emotional support visits ($p<0.001$) but not for other visits (which included physical health issues). Referrals onto specialist services greater for individuals with mood problems in the intervention group than the control group. |

Table 3: Quality Review Non-intervention Studies

| | Burns & Rapee (2006) | Chen, Mond & Kumar (2010) | Coles & Coleman (2010) | Cotton, Wright, Harris, Jorm, & McGorry (2006) | Mond, Marks, Hay, Rodgers, Kelly, Owen & Paxton, (2007) | Reavley, McCann, & Jorm (2012) | Reavley, McCann, & Jorm (2012) | Stansbury, Wimsatt, Simpson, Martin & Nelson (2011) | Swords, Hennessy, & Heary (2011) | Wright, Jorm, Harris & McGorry (2007) | Wright, Harris, Wiggers, Jorm, Cotton, Harrigan, Hurworth, & McGorry (2005) | Smith (2011) |
|---|----------------------|---------------------------|------------------------|--|---|--------------------------------|--------------------------------|---|----------------------------------|---------------------------------------|---|--------------|
| Rationale and Design | | | | | | | | | | | | |
| Was there a theoretical/conceptual basis for the study? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| Were aims and objectives clearly presented? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| Was the methodology described in a clear manner that would allow replication? | 2 | 2 | 2 | 2 | 2 | 1 | 1 | 2 | 2 | 2 | 2 | 1 |

| | | | | | | | | | | | | |
|--|---|---|---|---|---|---|---|---|---|---|---|---|
| Sub total | 6 | 6 | 6 | 6 | 6 | 5 | 5 | 6 | 6 | 6 | 6 | 5 |
| <i>Sample and Measures</i> | | | | | | | | | | | | |
| Was the study sample homogenous in type and severity of target problem? | 0 | 1 | 0 | 2 | 2 | 0 | 0 | 2 | 2 | 2 | 2 | 1 |
| Were reliable and valid measures used to measure variables, e.g. anxiety | 0 | 1 | 0 | 0 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 2 |
| Sub-total | 0 | 2 | 0 | 2 | 3 | 1 | 1 | 2 | 3 | 3 | 3 | 3 |
| <i>Results</i> | | | | | | | | | | | | |
| Were confounding variables controlled for? | 0 | 2 | 0 | 1 | 2 | 0 | 0 | 1 | 0 | 2 | 2 | 0 |

| | | | | | | | | | | | | |
|---|----|----|----|----|----|----|---|----|----|----|----|----|
| Were suitable statistical analysis employed? | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 0 | 1 | 2 | 2 | 2 |
| Was the sample size enough to detect meaningful effect? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 1 | 2 | 2 | 2 | 2 |
| Are the results generalisable across population? | 1 | 1 | 1 | 2 | 2 | 0 | 0 | 1 | 2 | 2 | 2 | 1 |
| Are the results generalisable across settings? | 1 | 1 | 1 | 2 | 2 | 0 | 0 | 0 | 2 | 2 | 2 | 1 |
| Subtotal | 5 | 8 | 6 | 9 | 10 | 4 | 4 | 3 | 7 | 10 | 10 | 6 |
| TOTAL | 13 | 16 | 12 | 17 | 19 | 10 | 8 | 11 | 16 | 19 | 19 | 14 |

Table 4: Quality Review Intervention Studies

| | Robinson, Gook, Yuen, Hughesm Dodd, Bapat, Schwass, McGorry & Yung, (2009) | Wright, McGorry, Harris, Jorm, & Pennell, (2006) | Costin, Mackinnon, Griffiths, Batterham, Bennett, Bennett, & Christensen, (2009) | Santor, Poulin, LeBlanc & Kusumakar, (2007) |
|---|--|--|--|---|
| <i>Rationael and Design</i> | | | | |
| Was there a theoretical/ conceptual basis for the study? | 2 | 2 | 2 | 2 |
| Were aims and objectives clearly presented? | 2 | 2 | 2 | 2 |
| Was the methodology described in a clear manner that would allow replication? | 2 | 1 | 2 | 2 |
| Was the study longitudinal? | 2 | 2 | 1 | 2 |
| If so, is it over a period longer than a year? | 1 | 2 | 0 | 2 |
| Did the study use a comparison group? | 2 | 2 | 2 | 2 |

| | | | | |
|--|----|----|----|----|
| If so, were initial group difference accounted for? | 2 | 2 | 2 | 2 |
| Were participants systematically selected (representative of the population) | 2 | 2 | 2 | 2 |
| Sub total | 15 | 15 | 13 | 16 |
| <i>Sample and Measures</i> | | | | |
| Was the study sample homogenous in type and severity of target problem? | 2 | 2 | 2 | 2 |
| Were reliable and valid measures used to measure variables, e.g. anxiety | 1 | 1 | 1 | 2 |
| Were variables used to measure outcome appropriate in relation to the study aim? | 2 | 2 | 2 | 2 |
| Sub-total | 5 | 5 | 5 | 6 |
| <i>Results</i> | | | | |
| Were confounding variables controlled for? | 2 | 1 | 2 | 2 |

| | | | | |
|---|----|----|----|----|
| Were suitable statistical analysis employed? | 1 | 2 | 2 | 2 |
| Was the sample size enough to detect meaningful effect? | 2 | 2 | 2 | 2 |
| Are the results generalisable across population? | 2 | 2 | 2 | 2 |
| Are the results generalisable across settings? | 2 | 2 | 2 | 1 |
| Subtotal | 9 | 9 | 10 | 9 |
| TOTAL | 29 | 29 | 28 | 31 |

Results

As the studies included in this review can be separated into two categories, namely non-intervention studies and intervention studies, they will be described in two separate sections. Firstly, non-intervention studies will be reviewed in order to set the scene with regards to general levels of mental health literacy and help seeking behaviour in young people. General findings will firstly be presented, followed by a critique of the studies based upon the quality assurance criteria grid.

Non-intervention Studies

The studies measuring mental health literacy and help seeking behaviours in young people showed several general trends. In studies comparing mental health literacy between genders, several found that females were significantly more likely to correctly label mental health difficulties e.g. depression and anxiety compared to their male counterparts (Burns & Rapee, 2006; Coles & Coleman, 2010; Wright, Jorm, Harris & McGorry, 2007 and Cotton, Wright, Harris, Jorm & McGorry, 2006). Burns and Rapee (2006) also found that gender of the vignette also appeared to influence recognition of symptoms of depression; with symptoms being identified more readily when described in relation to the male character.

Several of the studies stratified the participants by age, which produced some interesting comparisons. Being older in age was also found to significantly increase

the likelihood of correct labelling of mental health difficulties and subsequent identification of appropriate sources of help (e.g. Swords et al, 2011; Wright et al, 2007; Cotton et al, 2006). Wright et al (2007) specifically identified that younger participants were significantly more likely to identify inappropriate strategies, such as the use of alcohol, as a means of dealing with mental health difficulties.

Overall, correct recognition of mental health difficulties appeared to increase the likelihood of young people being able to identify appropriate sources of support (Chen, Mond & Kumar, 2010; Wright et al, 2005; Wright et al, 2007). These findings fit with the pilot study conducted by Smith (2011), which identified the domains of mental health literacy which most significantly influenced help-seeking behaviours in young people were knowledge and beliefs about mental health difficulties (including cause and prognosis), and knowledge about suitable services and interventions. A consistent finding across studies was that young people found identification of psychosis most difficult compared to other psychopathologies (Cotton, et al, 2006; Wright, et al, 2005; Wright, et al, 2007), perhaps because it is less common than other disorders.

The sources of informal support for help with mental health difficulties most frequently selected by both males and females were talking to family or friends (e.g. Burns & Rapee, 2006; Reavley, McCann & Jorm, 2012; Mond et al, 2007). Counsellors and psychologists were the most likely sources of formal support (e.g. Burns &

Rapee, 2006; Chen, Mond & Kumar, 2010; Stansbury, Wilmsatt, Simpson, Martin & Nelson, 2011). Interestingly, differences were found in young people's attitudes to seeking support for mental health difficulties from their GP. Burns & Rapee (2006) and Swords, Hennessy & Heary (2011) reported that young people did not rate seeking support from GP as a desirable option whereas other studies found participants rated seeking advice from their GP as being one of their most likely options (e.g. Reavley, McCann & Jorm, 2012; Stansbury et al, 2011). Young people also rated vitamins and minerals highly when asked to identify appropriate medications for disorders presented. This was consistent across several disorders including depression (Cotton et al, 2006), eating disorders (Mond et al, 2007) and anxiety (Coles & Coleman, 2010).

In terms of prognosis, several studies found that young people indicated that they believed that recovery from the mental health difficulty was possible with appropriate support but relapse would probably occur (e.g. Chen et al, 2010; Mond et al, 2007).

Studies found that participants who were deemed to have similar psychopathology to the mental health difficulty depicted in the vignette (e.g. Bulimia Nervosa) were less likely to correctly label the disorder and were also less able to identify appropriate forms of support (Chen et al, 2010; Mond et al, 2007).

Rationale and Design

A particular strength of the papers was that they all consistently and clearly described the theoretical and conceptual foundations upon which their studies were based. All papers cited Jorm et al (1997) conceptualisation of mental health literacy and help seeking behaviour and stated how this had led to the development of the aims for their research papers.

There was an overall consensus amongst authors that the rationale for conducting research in this area was to extend the knowledge base with regards to understanding mental health literacy in young people, building upon research previously conducted within an adult population (Jorm et al, 1997; Jorm et al, 2003).

Within the reviewed studies, various domains of mental health literacy were investigated including young people's knowledge and beliefs about mental health difficulties and their prognosis, and associated help seeking behaviour. All papers investigated both informal help seeking as well as formal help seeking in young people.

Cotton et al (2006) used gender as an independent factor. Predominantly the rationale for this was that past research has found that males are less likely to seek support for mental health difficulties (e.g. Eckert, Kutek, Dunn, Air & Goldney, 2010;

Biddle, Gunnell, Sharp & Donovan, 2004) and it was hypothesised that poorer mental health literacy could be a factor driving this discrepancy.

Swords et al (2011) who recruited participants from a wider age range also stratified their findings into age groups, thus enabling any age related differences in mental health literacy to be identified. Stansbury et al (2011) looked specifically at mental health literacy and help seeking in African American College students as it was identified that historically that this is a population that experiences mental health difficulties without seeking help. Investigating mental health literacy within different sub-groups of young people suggests that the research agenda is beginning to diversify, looking more specifically at populations who may be deemed to have poorer mental health literacy including help seeking.

Sample and measures

To measure mental health literacy and help seeking behaviour, all studies reviewed (apart from Burns & Rapee, 2006 and Swords et al, 2011) developed questionnaires based upon the work of Jorm et al (1997). The original Mental Health Literacy Questionnaire (Jorm et al, 1997) was developed for use within an adult population and focused specifically upon depression and psychosis. Thus all of the studies under review presented modified vignettes to participants. Modifications included changing presenting difficulties, e.g. making them relevant to different disorders e.g.

anxiety (Coles & Coleman, 2010), or bulimia nervosa (Chen et al, 2010; Mond et al, 2007). This was achieved by creating vignettes which depicted characters with symptoms consistent with the relevant DSM-IV criteria; changing the vignette characters names to make them culturally sensitive (Stansbury et al, 2011); and to reflect situations which young people would encounter (such as having trouble at school) instead of adult situations depicted in the original questionnaire (Burns & Rapee, 2006).

Although a relatively consistent approach to measuring mental health literacy and help seeking behaviour was taken throughout the studies, some methodological issues were not addressed. For example, the original questionnaire developed by Jorm et al (1997) has never been formally validated. The questionnaires used within the studies reviewed for this paper subsequently have not been validated or have any normative values for mental health literacy in young people. Thus, it is difficult to ascertain whether the results obtained in the studies are reliable and valid and whether they are generalisable to young people as a whole. Therefore, any results must be tentatively interpreted.

Swords et al (2011) created their own vignettes which were reviewed by 14 clinical psychologists to determine their suitability for use within the study. Although this potentially improved the vignettes' face validity, it would have been informative to have the vignettes reviewed by young people. Out of all of the studies reviewed not

one developed vignettes in consultation with young people which is a potential weakness. This would have, for example, helped to ensure that the language used to describe symptomatology was suitable for the target audience.

A further limitation was that despite being published as separate studies, three of the studies reviewed were found to be drawn from the same data set (Wright et al, 2005; Cotton et al, 2006; Wright et al, 2007); although they did have slightly different aims regarding how the data was being analysed. This perhaps reflects how under-researched this area is.

A further potential limitation was that some studies (e.g. Wright et al, 2007) recruited participants whose age range spanned between 12 and 25 years of age. Although these studies stratified the young people into age groups, there appeared to be no attempt to amend the language of the vignettes according to age. This may therefore have impacted upon the results reported, potentially skewing the recognition rates of symptomatology.

Additional valid and reliable measures were incorporated into some of the studies. For example, Chen et al, (2010) who investigated mental health literacy relating to bulimia nervosa also used the Eating Disorder Examination Questionnaire (EDE-Q; Fairburn & Beglin, 1994) to ascertain levels of eating disorder psychopathology in

participants. They used this measure as a way of stratifying participants to investigate differing responses between those who exhibited symptomatology versus those participants who did not.

In terms of measuring help seeking behaviour three studies required participants to self-generate sources of support which they would recommend for common mental health difficulties (e.g. Burns & Rapee, 2006). Others, (e.g. Reavley, McCann & Jorm, 2012, b) provided lists of support, both formal and informal, from which the participants were required to indicate which ones they believed were most appropriate. Young people who self generated answers would be relying solely upon their own knowledge and this would perhaps give a better indication of baseline levels of mental health literacy and help seeking behaviour. Those participants who were asked to choose from a list may have picked what they considered desirable responses, or may have been prompted to pick support services which they may not necessarily have thought about if they were in a situation which required them to identify support for their own mental health difficulties.

For the most part, participants were required to indicate what sources of support they would recommend for the character in the vignette. Although this enables knowledge of services and sources of support to be ascertained, it remains a hypothetical scenario. None of the non-intervention studies were longitudinal in nature, there is therefore no way to ascertain whether young people who

experience similar difficulties to those depicted in the vignettes would take action and follow up on these sources of support; and therefore whether knowledge of services or support translates into actual help seeking behaviour.

Results

Most of the studies used non-parametric tests, such as chi-square, to analyse data. This was deemed appropriate as the assumptions which govern the use of parametric statistics would have potentially have been violated due to arbitrary Likert scales being used and the data sets thus being ordinal. Burns & Rapee (2005) and Swords et al (2011) both opted to not use non-parametric tests, instead opting to use ANOVA to analyse their ordinal data sets. This therefore resulted in the studies obtaining a lower quality rating, as it was felt that potentially the assumptions of using parametric statistics may have not been met and alternative non-parametric statistics may have been more appropriate. Stansbury et al (2011) scored zero for their use of appropriate statistical measures as no inferential statistical measures were used, with only descriptive datum being presented.

There were some limitations with regards to the samples of participants recruited. Several of the studies included more female than male participants (e.g. Cotton et al, 2006; Reavely et al, 2012; Stansbury et al, 2011). Others recruited only females (e.g. Chen et al, 2010; Mond et al, 2007). This therefore makes it difficult to ascertain a

true picture of mental health literacy and help seeking behaviour across genders and potentially limits generalisability of results to young people as a whole.

The non-intervention studies reviewed within this paper were predominantly conducted in Australia (nine out of thirteen). This also potentially affects generalisability and applicability of findings to a UK population. Consideration should also be given to the differences in health care systems between countries, for example, having to self-fund treatment in countries such as the USA and Australia could impact upon the rates of help seeking behaviour from formal sources such as GP's or Psychologists as it may be that individuals in countries where health care has a cost may utilise informal sources of support instead.

Recruitment of participants was through opportunity sampling which may have also reduced generalisability to other contexts or groups. For example, some studies recruited psychology students to participate in their studies (e.g. Chen et al, 2010 and Coles & Coleman, 2010). The participants obtained research credits for agreeing to take part. Although not explicitly discussed within the papers in question, it is reasonable to assume that as psychology students they would have had increased knowledge of mental health difficulties and help seeking behaviour compared to their peers.

A further limitation of the studies included in the review is that there was little investigation of what experience the participants or someone they knew had of mental health difficulties or sources of support. Experiences such as these could have influenced knowledge and beliefs about mental health difficulties (e.g. triggers or prognosis) and sources of support.

Intervention studies

The aims of the intervention studies were to increase levels of mental health literacy to increase help-seeking behaviours; therefore building upon the findings of the non-intervention studies previously reviewed. The overall findings will be presented followed by a critique based upon the quality criteria ratings presented previously (table 3 and table 4).

Overall findings

Four intervention studies were identified and reviewed. Each of the studies implemented an educational based programme to enhance participants mental health literacy in order to increase the possibility of future help-seeking behaviour. Information was disseminated to participants in various ways. Robinson et al (2010) and Santor et al (2007) conducted educational based workshops; Costin et al (2009) sent participants e-mail links to web-sites comprising of information regarding

mental health difficulties; whereas Wright et al (2006) took a multi-media approach (e.g. cinema adverts) targeting the whole community.

Results were mixed, with the educational based workshops appearing to demonstrate more favourable changes particularly for increasing intentions to seek help for mental health difficulties. Although, due to a limited number of intervention studies for review, these results have to be interpreted cautiously. Robinson et al (2010) reported that following workshops participants were significantly more likely to report that they would seek help for mental health difficulties if they were to experience them. They were able to demonstrate an increase in help seeking intentions in participants who had received the intervention compared to the control group. This difference was negated following the wait list control group receiving the intervention with both groups indicating greater intentions to seek help should the need arise compared to baseline scores. In terms of mental health literacy no significant differences in identification of depression were found post-intervention. However, the authors noted that baseline knowledge of mental health difficulties amongst the participants was high at baseline suggesting that there may have been a 'ceiling effect'.

Santor et al (2007) measured actual help seeking behaviour (rather than intentions to seek help) which was a unique aspect of this study. Similar to the findings of Robinson et al (2010) they also reported significant increase in young people seeking

help following receiving educational intervention. They also reported that young people who obtained higher scores on the Beck Depression Inventory (BDI; Beck & Steer, 1997) sought help more frequently post intervention.

Wright et al (2006) found that following the mental health campaign the intervention group appeared to show increased mental health literacy (e.g. in terms of recognition of symptoms of depression) and reported help-seeking for mental health difficulties.

Costin et al (2009) reported disappointing results, finding that their method of using a web-based intervention programme provided no evidence of increasing mental health literacy or help seeking behaviour. They did however find that post intervention participants from both groups rated seeking help from professionals for mental health difficulties as being more helpful when compared to pre-intervention scores. An interesting finding was that both pre and post intervention participants scoring higher on Kessler Depression Inventory (Andrews & Slade, 2001) and who were therefore assigned to the high distress group were found to have more knowledge regarding help seeking from professional sources.

Although this study intended to measure whether there was change in actual help seeking behaviour a potential weakness in the methodology used was that the

follow-up period of three weeks appears too short to have been able to capture any real change.

Rationale and design

The theoretical basis of mental health literacy and associated help seeking behaviour outlined within all of the studies was again firmly based within the conceptualisation developed by Jorm et al (1997). All studies therefore scored highly when the quality of this domain was being assessed. This grounding led to consistency with regards to the aims formulated for each of the studies.

A strength of the intervention studies was that they were conducted over longer periods of time. For example, Santor et al (2007) evaluated changes in mental health literacy and help seeking behaviour post intervention over eight months. Wright et al (2006) community awareness programme was implemented over 14 months.

A range of designs was used for data collection. A strength of the studies was that the authors justified the reasons for the design which they had chosen. For example, Santor et al, (2007) used a non-randomised controlled trial to enable the intervention to be embedded within one particular school year; with pupils in the intervention group receiving information as part of school health lessons. Pupils in the school years above and below the intervention group were subsequently used as

the control group. The authors argued that using pupils in the years above and below the intervention group would help to negate any cohort effects. Extra measures were taken to ensure that there were no differences between groups that could account for differences in mental health literacy and help-seeking behaviour. For example, the Beck Depression Inventory (BDI, Beck & Steer, 1997) was completed by all participants pre-intervention, enabling the authors to conclude that no differences in psychopathology existed between the pupils in each group.

Wright et al (2006) selected two geographical areas in Melbourne, Australia, one to act as a control group and one as an intervention group. The areas were chosen due to their similar demographics. Following a 14-month multi-media mental health awareness programme delivered to the intervention group only, they subsequently used a cross-sectional design to randomly select participants from both areas. The use of this design enabled them to determine the effectiveness of this programme on mental health literacy and help seeking behaviours.

Costin et al (2009) was the only Randomised Controlled Trial (RCT) reviewed and therefore scored highly for this domain on the quality assurance checklist. RCT's are considered the gold standard methodological approach for determining cause and effect of an intervention. The authors endeavoured to randomise participants to conditions according to both psychopathology (dividing participants into high and low distress groups) as well as by gender.

Sample and measures

The age range of participants in certain studies was large. For example, Wright et al (2006) recruited young people aged 12 to 25 years, whereas Santor et al, (2007) recruited participants aged 14 to 16 years. This made direct comparisons between studies difficult.

The measures for mental health literacy and help seeking behaviour were the same as outlined for the non-intervention studies; namely the use of vignette based questionnaires requiring participants to identify symptomatology and suitable sources of support for the difficulties outlined based upon the mental health literacy questionnaire devised by Jorm (1997). A limitation of these studies was that the measures used for assessing improvement of mental health literacy and help seeking behaviour were again based upon un-validated measures. The intervention studies therefore also obtained poor quality ratings for this domain.

Several of the intervention studies utilised additional psychometric measures as a means to determine whether, for example, underlying psychological distress such as depression influenced participants responses. Although not directly measuring the variables in question (namely help seeking behaviour and mental health literacy) they did enable additional confounding factors such as depression to be taken into account and for participants responses to be analysed accordingly. For example,

Santor et al (2007) incorporated the BDI (Beck & Steer, 1997). The BDI Questionnaire is a validated and reliable measure, which reports good psychometric properties (Beck, Steer & Garbin, 1997). Costin et al, (2009) also incorporated the Actual Help Seeking Questionnaire (AHSQ; Rickwood et al, 2005) to assess whether participants had sought help post intervention.

All of the intervention studies used pre-test and post-test measures of mental health literacy and help seeking behaviour. Thus changes in mental health literacy and help seeking behaviour could be more easily attributed to the intervention implemented. Robinson et al, (2010) implemented a two hour psycho-educational intervention for boys aged 14-16 years. This study employed a wait list control group which improved the design of the study as it enabled comparison of baseline scores of mental health literacy and help seeking behaviour with scores obtained after the first group had received the training and then with follow-up scores after both groups had received the training.

Results

In terms of quality ratings, the intervention studies fared better than the non-intervention studies. Predominantly, the intervention studies all described how they had tried to control for confounding variables such as gender or psychopathology.

All studies scored highly for their appropriate use of inferential statistical tests in their respective data analyses. Several of the studies used binary logistic regression to analyse data. This was deemed appropriate as questions asked of the participants required “yes” and “no” responses. Data was therefore nominal, consisting of dichotomous variables. Wright, et al (2005) used Chi-square tests which was considered appropriate due to the data being non-parametric frequency data.

Wright, et al (2006) completed Cohen’s power calculation to enable a suitable sample size to show effect of intervention to be ascertained. All studies reported fairly substantial sample sizes. However, as research in this area progresses, it would be beneficial for larger, more heterogeneous samples to be recruited so that it could be determined with increased confidence that the intervention was targeting the variables of interest. Costin et al (2009) commented that it was difficult to recruit participants for their study, thus participant numbers (N=348) were lower than desired. This potentially reflects the methodology used for recruitment (a postal questionnaire sent to young people, N=12,000) from the Australian Electoral Roll. This led to a response rate of just 14% (N=1,764). Further participants were lost due to some deciding not to continue with the research after the initial stage (N=542) and subsequently participants (N=423) were randomly sampled not to progress to enable equal numbers of participants to be allocated to conditions.

It appears that other studies had fewer problems with recruitment and retention of participants. For example, studies that were conducted in school settings with interventions being embedded within school curriculum, such as Santor et al (2007), did not report difficulties with recruitment or retention of participants.

Generalisability

The intervention studies scored highly for external validity. This was for several reasons including attempts to control for independent factors such as levels of distress or gender (e.g. Costin et al, 2009) and use of control groups to demonstrate effects of interventions upon mental health literacy and help seeking behaviour (e.g. Santor et al, 2007; Wright et al, 2006).

There are however some potential issues with regards to generalisability across populations and contexts. Costin et al (2009) for example found their method of recruitment (postal survey) led to a low response rate. This therefore may reflect a selection bias for young people opting to participate in the research. The generalisability of these findings to the rest of the population may therefore be limited.

Santor et al (2007), tracked students actual visits to school counselling services; however help seeking is predicated upon there being support available in all schools.

This therefore may limit the generalisability of the results to other contexts if counselling services are not available.

Discussion

The findings reported in the studies included in the current systematic review will be considered in the context of their methodological strengths and weaknesses and clinical and research implications will be discussed.

Clinical implications

The papers reviewed within this literature review suggest that mental health literacy and subsequent help seeking behaviour in young people varies due to several factors, including age, gender and presenting mental health difficulty. Specifically, females were found to be more able to identify mental health difficulties than males. Results also suggest that being older in age is positively related to mental health literacy and the ability to identify appropriate sources of help. Certain mental health difficulties, such as psychosis, appeared to be less identifiable. Identifying sub-groups of young people for whom poorer mental health literacy may create a barrier to help-seeking, or indeed identifying mental health difficulties of which young people are less knowledgeable, could lead to targeted interventions being developed and implemented.

Rickwood, et al (2005) propose that help-seeking can be conceptualised as a series of steps from the individual's initial recognition of a mental health difficulty; through to a problem-solving stage which involves the individual weighing up the potential solutions, including the formal and informal options of interventions available to them; through to knowing how to access these help sources. At each step, the individual is required to possess a certain level of knowledge regarding mental health difficulties and the help-seeking process, without which they are unable to pass through to the next stage thus restricting their abilities to adequately seek help. This appears to be a model from which results obtained in this review could be based.

Papers that stratified results into age groups found that younger participants had poorer mental health literacy and knowledge of sources of support. This difference may be explained by older participants having had more experience of mental health difficulties or education. Younger individuals may therefore be less likely to be able to identify if they are experiencing mental health difficulties, or, even if they do, how to go about accessing appropriate support. Clinically, this suggests that this could be a sub-group who may not be accessing mental health services in a timely fashion and is an area which could be investigated and subsequently targeted.

One of the major limitations of the studies reviewed was that they measured identification of mental health difficulties in others (i.e. through vignettes) rather than participants identifying symptoms they were experiencing themselves.

Moreover, intent to seek help, or recommendations of support to others was the predominant variable measured, rather than *actual* help-seeking behaviour. These are limitations that need addressing in the future, so as to ascertain whether ability to recognise symptomatology and possessing knowledge regarding recommended interventions translates into *actual* help-seeking behaviour.

When asked where they would seek help if they experienced mental health difficulties, the most frequently chosen sources of informal support by young people was parents, particularly mothers, and close friends. Increasing mental health literacy and knowledge regarding help-seeking needs to be increased in these potentially helpful others to enable them to identify and immediately and appropriately deal with the psychological difficulties of young people in their family and social systems. A potentially large, influential and ever-present support network is under utilised so long as parents and young people have low levels of mental health literacy and knowledge of how to seek help as they will remain ill-equipped to provide advice and support to distressed young people in their immediate circle. This issue is beginning to be addressed through research conducted by e.g. Jorm et al (2007) who has begun to develop and implement Mental Health First Aid Behaviour programmes which aim to increase knowledge of mental health disorders (including recognising symptoms, and appropriate interventions) in those most likely to be acting as informal sources of support (e.g. parents, peers); and how those acting as informal sources of support can aid individuals in seeking help when required.

Counsellors and psychologists were the most common sources of formal help chosen by young people. However, participants were not asked how they would go about accessing this type of support. Clinically, this is an important factor to consider as, if the pathways to accessing support are not clear or the availability of such services is compromised for any reason, then despite the young person *knowing* what would be helpful, it may impact upon them *accessing* such support. Previous research (Biddle et al, 2006) has found that many young people are not aware that they are able to approach their GP for advice on mental health difficulties they viewed their GP as only dealing with physical health difficulties. Also, some young people have been found to lack confidence and trust in their GP (Leavely et al, 2011). This may account for the finding that GP's were consistently chosen at a lesser rate compared to other professionals which is concerning as often GP's are the first stage in the pathway to accessing mental health services. This finding has implications for how GP practices design and present their public relations materials.

Future research

Quality analysis of the papers revealed that one of the main methodological weaknesses concerned the measures of mental health literacy and help-seeking behaviour in young people. The frequently used clinical vignettes were changed in each case without thorough rationale or piloting, thus reducing consistency and potentially their reliability and validity. Thus, the main limitation identified within the review was that the measures remain un-validated and no normative data is as yet

available. Time and effort needs to be invested into developing validated measures to assess mental health literacy and help-seeking behaviours for use in future studies.

Generalisability of results across contexts was also identified as a weakness of the studies reviewed. This quality issue was predominantly due to participant recruitment procedures, particularly in those studies which recruited participants from relatively homogenous minority groups (e.g. psychology students). Few of the intervention studies were RCTs and thus did not take into account uncontrolled variables. Finally, the majority of the studies were conducted in Australia and America. Consideration should be given to the different health care systems in operation in different countries (e.g. private versus public health care) and the impact that different systems may have on individuals accessing services. For example, it could be that those who have to self-fund health care such as counselling may rely more heavily upon informal sources of support due to financial considerations. Future research should therefore be conducted in different contexts, including the UK, to enable these issues regarding generalisability to be addressed.

It appears that there has been little consultation with young people with regards to how to measure help-seeking behaviour and mental health literacy. It may be beneficial to hold focus groups to test suitability of, for example, language used in vignettes and whether it is appropriate to use the same vignettes for all participants

in a research study irrespective of age, gender, previous experience, ethnicity and other participant characteristics. This type of consultation with young people who have accessed mental health services could throw light on what has helped them to recognise the difficulties they were experiencing and where and how they sought help. This could then inform future interventions.

Future research should investigate the best way to disseminate information regarding mental health literacy and help-seeking. The intervention studies included in the current review used several different methods including workshops, multi-media such as advertising, or access to information on the internet. There is no consensus with regards to which method is most effective in increasing mental health literacy and help-seeking behaviour. In this respect consideration may have to be given to different groups of young people. For example, males may value a different approach to education than females.

Consideration of psychopathology within participants requires more consistent control as this could be a significant confounding factor. The research reviewed also did not focus on specific disorders such as depression. Future research into different mental health difficulties would enable a more comprehensive picture to be developed according to specific disorders.

It would be beneficial to invest in research projects that are longitudinal in nature in order to further build upon the work of the findings of Santor et al (2007). This would allow investigation into whether increasing knowledge of mental health literacy and sources of support actually translates into help-seeking behaviour, or whether there are other barriers at work.

Conclusions.

Mental health literacy must be considered as one of several factors which impact upon a young person's help-seeking behaviour when they experience psychological problems. Although the studies reviewed here have addressed the predicting factors of mental health literacy and help-seeking behaviour and have investigated the efficacy of a number of interventions, methodological weaknesses, particularly concerning the measures used, prevent firm conclusions to be made. Further research in this area would enable clinicians to develop and deliver preventative and early intervention services by being able to identify the most vulnerable groups and the most effective ways in which to present mental health education and encourage young people to access informal and formal means of psychological support.

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RESEARCH PAPER

**WHAT ARE THE EXPERIENCES OF YOUNG PEOPLE WHO FOLLOWING
THEIR DISCHARGE FROM CHILD AND ADOLESCENT MENTAL HEALTH
SERVICES (CAMHS), DO NOT TRANSFER INTO ADULT MENTAL HEALTH
SERVICES (AMHS)?**

Abstract

Research regarding the transition point between Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services (AMHS) has primarily focused upon policy makers' and practitioners' views. This study investigated six young people's experiences of transition using an Interpretative Phenomenological Approach. Two superordinate themes emerged: Firstly, "Therapeutic relationship: We're in this together". This reflected their experiences of being in a therapeutic relationship with their CAMHS practitioner and how it evolved over time. It comprised four main sub themes: (1) "I don't want to talk to them", (2) "Please don't cut me off just yet", (3) "Am I ready to leave" and (4) "I don't want anybody else!". The second superordinate theme, "What will they think of me if I'm an adult with a mental health problem?" reflected the young people's experiences of emerging adulthood and their perception of stigma towards individuals with mental health difficulties. It comprised of four subthemes, namely, (5) "They can't find out", (6) "New chapter", (7) "Child versus adult", (8) "Will I be able to work?" These themes are discussed in relation to relevant psychological literature, augmented by consideration of potential limitations of the research, clinical implications and areas for future research.

Key words: Interpretative Phenomenological Analysis, transition, young people, CAMHS, AMHS.

Introduction

Young people in Britain who develop mental health difficulties and are referred for treatment within the National Health Service (NHS) have their treatment provided by Child and Adolescent Mental Health Services (CAMHS). The upper age limit for young people accessing CAMHS generally lies between the ages of 16 and 18 years after which, if they require further input, their care is provided by Adult Mental Health Services (AMHS). “Transitional youth” therefore refers to those young people who reach the age cut-off for CAMHS and at this point are either discharged from mental health services or are referred into AMHS.

The National CAMHS Review (Department for Children, Schools and Families and Department of Health, 2008) recommended that CAMHS should provide treatment for young people to their 18th birthday at least, and preferably until a developmentally appropriate time comes for the young person to be discharged. However, Singh (2008) found that the upper age limit for CAMHS varied between 16 and 21 years across regions in the UK. This regional variability could potentially results in a gap for those adolescents who require help between the end of CAMHS provision and the point at which they are eligible for adult services i.e. 18 years of age.

For those young people who require on-going help, a number of potential barriers to a successful transition to AMHS have been suggested. These include poor communication between child and adult specialist mental health services and a lack of joined up working which inhibits referrals being made, even when there is an identified need (e.g. Singh, Paul, Ford, Kramer & Weaver, 2008; Singh et al, 2010; Singh, Evans, Sireling & Stuart, 2005; Munoz- Solomando, Townley & Williams, 2010). Singh et al, (2010) found that despite referrals being made to AMHS, not all young people were accepted. Best predictors of being accepted included having a severe and enduring mental illness, the young person being prescribed medication at the time of transition, or if they had been admitted to hospital whilst receiving care from CAMHS. Interestingly, they found the young people least likely to be transferred into AMHS were those with difficulties classified as emotional, neuro-developmental or emerging personality disorders. Munoz- Solomando et al, (2010) echoed this finding reporting that AMHS provision often did not cover developmental disorders such as ADHD or ASD leaving some young people's needs unmet following discharge from CAMHS.

Adults who have diagnoses of mental health difficulties have been found to have been more likely to have experienced mental health difficulties during adolescence (e.g. Kessler et al, 2007; Hofstra, Van der Ende & Verhulst, 2002; Copeland, Shanahan, Costello & Angold, 2009; Kim-Cohen et al, 2003; Jonsson et al, 2011; Dekker et al, 2007). The potential detrimental effects untreated mental health

difficulties could have upon the young person's future (e.g. in terms of their social and occupational functioning) highlights the importance of young people being able to access appropriate support when required. Thus effectively managing transition between CAMHS and AMHS should be a priority to ensure minimum disengagement from services and enabling young people to be able to access appropriate sources of support when required.

Finally, NICE guidelines developed for common mental health disorders are often divided into child versus adult. This may pose difficulties since a young person may have reached the chronological age of 18, yet not have either the developmental, emotional or cognitive intelligence associated with adulthood, thus adult focused interventions may not be appropriate.

The difficulties associated with young people's transition between CAMHS and AMHS is not just restricted to the UK; rather it is a global concern. For example, US services to aid transition have been found to be sparse, again partly due to a lack of communication between child and adult services and differing referral criteria (Davies & Sondheimer, 2005; Davis, Geller & Hunt, 2006). Similarly in Australia, Cosgrave, et al (2008) found significant unmet mental health needs for young people (16-24years) which they attributed to the financial constraints on adult provision which forces services to cater only for young people with the most severe and

complex mental health difficulties. This finding may bear similarities to the difficulties in ensuring continuity of service provision in the UK.

In terms of understanding people's experiences of transition, research has largely focused on the perspectives of practitioners and policy makers (e.g. Taylor, Fauset & Harpin, 2010; Singh et al, 2008). Jivanjee, Kruzich & Gordon (2009) did however consider the difficulties of transitions from the viewpoint of parents. Parents in this study spoke about a lack of resources within the mental health system including a lack of psychiatric expertise amongst staff working with young people. They also described fear and frustration when trying to secure appropriate services for their children. A further finding was that parents often felt excluded if their child transitioned into AMHS.

Very little research has been conducted with young people with mental health problems themselves to discover what their experiences are (Dogra, 2005); particularly at the point of transition. Singh (2009) conducted a policy review of the transition of young people from child to adult mental health services and concluded that there were significant gaps within the literature specifically regarding the outcomes for young people who are not referred onto Adult mental Health Services (AMHS). Therefore this study sought to investigate young people's experiences following discharge from CAMHS without onward referral to adult services.

Method

Design

The aim of this study was to investigate young people's experiences of being discharged from CAMHS without having an onward referral to AMHS. Interpretative Phenomenological Analysis (IPA, Smith, Flowers & Larkin, 2009), a qualitative research method, was selected for the purpose of data collection and data analysis. IPA offers the opportunity to analyse datum at both an individual and then group level. The phenomenological orientation of IPA is concerned with the meanings people make of specific experiences which are emotionally salient. As IPA takes an idiographic approach, sample sizes are generally kept small to enable detailed analysis of the transcripts to take place. Utilising this approach enables rich data regarding the young people's lived experience to be elicited.

Through engagement with the participants narratives the researcher is able to take a double hermeneutic approach to analysis with the "researcher making sense of the participant who is making sense of X" (Smith, Flowers & Larkin, 2009, p. 35). In this case "X" (the common significant event) refers to young people's experiences of being discharged from CAMHS after reaching the age cut-off for the service without being referred on to AMHS.

Ethics

The research was approved by a local NHS ethics committee and by the Research and Development Team for the NHS Care Trust in which the research was to be conducted. The researcher also obtained an honorary contract with the NHS Trust, giving permission to conduct research within the trust. The study was sponsored by the University of Birmingham.

Participants

To ensure homogeneity of the participants, six young people (four females, two males) were recruited through one CAMHS team based in the West Midlands. Inclusion criteria were: participants were aged between 17 and 19 years of age, and that they had been discharged from CAMHS within the previous year without onward referral to AMHS. The only exclusion criterion was English not being the first language of the participant as the data was collected through semi-structured interviews. Good language comprehension and expression was therefore considered essential to collecting rich qualitative data, suitable for IPA.

Procedure

Potential participants were identified by professionals within the multi-disciplinary team. At discharge, if the young person met the inclusion criteria, they were asked by their CAMHS practitioner whether they would be interested in participating in

research being conducted in association with the CAMHS team. If they expressed that they were interested they were asked to read the participation letter (Appendix 1), and subsequently sign the opt-in slip. Their contact details were then added to a database held by CAMHS.

Following ethical approval and R&D approval being granted, the clinical psychologist based within the CAMHS team began to contact the young people who had expressed interest in participating in research. The clinical psychologist provided the young people with an outline of the research. The first eight young people contacted all expressed an interest in participating and gave consent for their contact details to be passed onto the researcher.

The researcher subsequently contacted these eight potential participants via telephone. They were once again given an outline of the study, and upon expressing that they would like to participate, a Participant Information Sheet (Appendix 2), was sent by post to the young person. One week later they were contacted by the researcher and if they still wanted to participate, an interview was arranged for a mutually agreed time at a convenient location. Six of the eight potential participants were available for an interview. The other two participants were unable to proceed due to University and exam commitments.

At the time of the interview, the young person was again given a verbal description of the research and given an opportunity to ask any questions they had. It was reiterated that the interview would be audio-recorded for the purpose of transcription and that each participant would be given code names to protect their identity. They were also informed that direct quotes from the interviews may be taken and published in the write-up so their participation was anonymous but not confidential. Each young person was asked to read and sign a consent form (Appendix 3) before the interview commenced. Participants were informed that they were able to withdraw from the study without any repercussions at any point up until two weeks following the interview. The interview took approximately one hour to complete. Participants were given a £15 high-street voucher to compensate them for their time, and reimbursed for any travel expenses which they had incurred as a result of participating in the research.

Characteristics of participants

Six participants were recruited to take part in the research study (characteristics outlined in Table 1). One participant attended CAMHS for just eight sessions. However, the average number of years which the other five participants attended CAMHS was for two and a half years.

Table 1: Participant Characteristics

| Gender | Pseudonym and ages of participants | Presenting difficulties at time of referral |
|----------|--|---|
| 4 female | Angela, 18 Lisa, 19 Phoebe, 19 Emma, 18 | Anxiety Depression OCD Eating Disorder |
| 2 male | Ben, 18 John, 19 | |

Interviews

Semi- structured interviews were conducted with each of the young people. An interview schedule (Appendix 4) was devised, in line with the IPA format, and formed the basis of the questions asked in the interviews.

Each interview was subsequently transcribed verbatim. However, any identifying information was removed (e.g. therapist names) and each participant was given a pseudonym to ensure anonymity.

Analysis

The interpretative component of IPA is firstly completed on a participant by participant basis, enabling the researcher to become fully immersed within the

narratives of each participant. Individual transcripts are read and re-read to enable the researcher to become familiar with the structure and content of the narratives leading to the researcher becoming fully immersed within the data set (Smith, Flowers & Larkin, 2009).

Phenomenological coding (Smith et al, 2009) is completed which involves detailed, systematic line by line coding of participants experiential claims, concerns and understanding of the experience under investigation. To connect with the participants' lived experience, the researcher must attempt to suspend their own judgement and beliefs about events when coding. The researcher must also refrain from interpretation before coding is completed in order to stay as true as possible to the young person's own narrative of the situation. The researcher achieves this by "bracketing off" any pre-conceptions or early interpretations through reflection and making notes separate to the transcript (Smith et al., 2009). A reflexive account produced by the researcher can be found in Appendix 5. This account aims to outline the researcher's background and experiences which could have potentially influenced data interpretation if this procedure of bracketing off had not been followed.

Upon completion of initial coding, the interpretative level of analysis is embarked upon by the researcher. This involves the researcher beginning to identify emerging themes within the individual transcript. The researcher proceeds to create a

“dialogue” between themselves, the coded data and the psychological knowledge that the researcher holds to interpret why the participants may have experienced and interpreted the event in the way that they did (Smith, 2004).

After completing this coding process a list of sub-themes is compiled for each of the individual transcripts. Sub-themes from all transcripts are subsequently drawn together to form clusters. The final step is to bring clusters together under superordinate themes. These themes then reflect the main experiential claims of the participants.

In order to ensure validity of the interpretation the researcher ensured that the emerging themes were discussed with their supervisor who has particular expertise in conducting IPA research. The researcher also joined a peer IPA group which offered opportunity to present sections of transcripts which were then independently coded by peers enabling alternative perspectives to be ascertained. However, despite using procedures such as triangulation to increase inter-rater reliability it is important to acknowledge that the interpretation of the data set is largely the researchers own. It is therefore possible that the data set may have been interpreted differently by different researchers.

Results

Following analysis two superordinate themes were identified. The first: “Therapeutic relationship: We’re in this together!” was made up of four sub-themes. The second: “What will they think of me if I’m an adult with a mental health problem?” was also made up of four sub-themes. The following table sets out the structure of the themes in more detail, and the information in brackets indicates the number of young people who contributed to each theme.

Table 2: Theme structure

| Superordinate themes | Subordinate themes |
|---|--|
| Therapeutic relationship: We’re in this together! (6 young people) | <ol style="list-style-type: none"> 1. I don’t want to talk to them! (5 young people) 2. Please don’t cut me off just yet! (6 young people) 3. Am I ready to leave? (6 young people) 4. I don’t want anybody else! (4 young people) |
| What will they think of me if I’m an adult with a mental health problem? (6 young people) | <ol style="list-style-type: none"> 5. They can’t find out! (6 young people) 6. New chapter (6 young people) 7. Child versus adult (6 young people) 8. Will I be able to work? (5 young people) |

Therapeutic relationship: We're in this together.

A superordinate theme woven throughout the young people's narratives was one concerning the therapeutic relationship. Developing a strong therapeutic relationship with their CAMHS practitioner enabled the young people in this sample to engage with the therapeutic process with positive results. It also enabled them to feel supported when discharged from CAMHS. However, when talking about discharge from CAMHS they also described feeling a loss that was particularly related to the therapeutic relationship coming to an end.

1. I don't want to talk to them...

All of the young people in this sample had been referred to CAMHS by their GP. In all cases this referral was instigated by parents who took their children to their GP due to concerns regarding their behaviour or mental health.

It appeared that at the time of referral the young people had little knowledge regarding what attending CAMHS would be like or how CAMHS could help them with their difficulties. This seemed to cause the young people to feel apprehensive. For example, Phoebe reflected: "I didn't know what they were going to make me do. I had no idea what was goin' to happen. It worried me to be honest".

Powerful statements were used to describe how they had felt prior to their first appointment. For example: “feeling terrified” (Lisa), and “dreading it” (Angela). Lisa elaborated further, linking her apprehension to being unsure what she would be expected to say to her CAMHS practitioner: “I was like oh my god, this woman is going to ask me things about my life, I don’t know what I’m going to tell her.” Similarly, Angela spoke about feeling “embarrassed” as she did not want to discuss her difficulties with others: “Like, I didn’t want to go in the first place. I didn’t really wanna talk to anyone else about it.”

Analysis of the young people’s narratives revealed a dramatic shift from this initial apprehension about attending CAMHS to a feeling of relief and positivity once they had a better understanding of what to expect. For example, Angela said: “But I think after my first session, I knew that it was fine and that it was going to be okay me going there.” And Phoebe reflected: “But it was okay you know. It wasn’t nearly as bad as I thought. It helped that they (CAMHS practitioner) was nice.”

The practitioners’ abilities to engage and build rapport appeared to have been important for the young people to feel comfortable attending CAMHS. For example they described feeling as though their difficulties were understood: “Well it was good having someone to talk to, like someone who understood what it was like” (Julie); felt in control of the direction of therapy: “you took control over what you

talked about, and they would follow” (Lisa); and not judged: “So it was like I could say anything in that room and know that it was fine” (Angela).

This engagement is further illustrated by the positive feelings they described when discussing their practitioner: “I had such a good relationship with (my practitioner)” (Angela). Emma elaborated on this further:

“Like her knowing me really helped. I could go into a session, and explain what happened and she would know how I would have reacted, how I would have felt without me having to say, I think that really helps when you’re not 100% sure of your own emotions. When you feel unsteady. And especially when you’re in a dark place and don’t feel like you can rely on people. I think I really benefitted from feeling like I had someone I could rely on. And someone I could turn to.”

The young people’s engagement with the therapeutic process is also reflected in their descriptions of the positive outcomes of therapy. For example: “I really felt that (CAMHS) has been a massive help to me ‘cos without them I probably would be still depressed now.” (Ben). And: “It was good you know. I was there (CAMHS) ages but I did get better. It did help” (Phoebe).

2. Don’t cut me off just yet...

All of the young people reported that their CAMHS practitioners had told them that the service only provided support until the age of 18. Four of the young people

described initially feeling concerned at the thought of not being able to continue to attend after they turned 18. For example, “they kinda mentioned that you know that I’d be at the cut- off point when I turned 18, and that worried me a lot” (Emma).

However, the young people described that their practitioners were flexible and their discharge from the service was planned around their individual needs. Angela reflected: “(CAMHS practitioner) said “I won’t cut you off. The moment you’re 18, we won’t cut you off”. Similarly Julie said: “So it wasn’t like being abandoned at the end of it.”

This flexibility about ending and being kept on after age 18 appeared to offer emotional containment for some and appeared especially important to those who turned 18 early in their final school year and had A-levels to complete. For example: “I think it helped, I think, I think (my CAMHS practitioner) did make the right decision about keeping that door open for a while” (Lisa), and

“But if your being just cast off into the big wide world, yeah I would have felt scared... especially as you know I was coming to the end of sixth form, about to get exam results and finding out if I’m going off to university, they’re like big major things in your life.”

(Emma)

“I was like a bit worried to be honest. I thought “I’m an adult” are they going to like kick me out? But ‘cos there was loads goin’ on, like with my exams and that they didn’t. I stayed ‘till I went to uni.”

(Phoebe)

Five of the young people described why keeping them on in the service after turning 18 was so important to them. For example, Lisa reflected that she believed there would be negative ramifications if she had been discharged as soon as she had turned 18: “Erm, if it had ended then, then I probably would have doubted my capabilities, I wouldn’t have got into uni. I wouldn’t be doing what I wanted to do”.

And similarly, Phoebe reflected,

“they kept me on and I think on their behalf that that was a good decision. Looking back at it ‘cos if they’d discharged me then, if I’d said no I’m ok I’m dealing with things, I wouldn’t have been able to continue and then I wouldn’t have been able to cope with things and I would have been in a mess.”

Emma described how she would have felt “angry” towards CAMHS if they had discharged her as soon as she reached 18: “I would have been really angry. I would have probably have been like, you’ve supported me from such an early age, you can’t just cut me off! I would have felt let down, really let down.”

Emma went on to describe an interesting difference between how she would have perceived being told that she was *no longer able* to attend CAMHS due to her age,

rather than being told that she was being discharged because she had made significant improvement and was *ready* to leave:

“I think in my mind, saying we cant see you anymore, there’s no reassurance that you’re okay, that’s just ‘we cant see you anymore because its outlined here in paragraph 51’ [Policy], you know that we cant.. it would have been a big difference in my mind. Just, I would have always doubted you know, maybe I do still need to see them. Maybe I’m not ready for this. Maybe I’m not prepared to go on without any support. They’ve said they can’t see me anymore, well I can’t do it on my own. Whereas saying we don’t need to see you anymore, it’s reassurance, its backing up that you’re okay. And you can go on, you’re able to cope with things, you’re able to deal with situations that might come about in your life. And you feel that they that they also agree with you’re thinking of yes you’re okay, you can deal with this.”

3. Am I ready to leave?

When it came to discharge, all of the young people spoke about being ready to leave the service without needing referral to AMHS. Julie reflected: “So by the time it was up I didn’t really need to go anymore.” Similarly, Phoebe said: “I was ready to go to be honest. I didn’t think I needed to see anyone else.” And John reflected: “I was in the right place at that time to finish.” Emma used the analogy of “graduating” to signify that she no longer needed input from mental health services:

“But when they turned around you know, not long after my 18th birthday and said we don’t need to see you anymore then you think “I’ve done it”. I’ve graduated from the mental health service <laughs>. You know you feel like your ready to go on.”

However, although acknowledging that they were ready to leave, there was still a distinct sense of ambivalence within their stories with regards to the CAMHS sessions ending. For example, Angela talked about being both excited and scared when she thought about leaving CAMHS:

“I was kind of excited in the fact that you know I’m going to be finishing. I can handle this on my own now. I can do it. But in a way. But in a way I was scared, because I didn’t know what I was going to be like, you know what would happen if I was poorly again erm.. it was just the uncertainty. But that’s life isn’t it?”

The feelings of apprehension appeared to be stronger for the five young people who had received input from CAMHS for an extended period of time. This may have been because they had become accustomed to attending CAMHS. Their narratives suggest that they become dependent upon their practitioner and the support which they had provided. For example, Phoebe: “I thought you know, you’ve helped me kinda develop for this many years of my life and now it’s just gone.” John: “It was normal to me. You know touching base with someone every so often, and I thought you know, I haven’t got that anymore. Who am I supposed to talk to? It was a bit overwhelming.” Angela: “But then when it was gone, it was like Oh my god it’s gone. What do I do now?” and for Lisa:

“It was a bit sad if I’m honest <laughs>. I was just like “oh, this is the end of it”. It didn’t kick in until a while after, like a few hours after and I was like, I got upset. I thought “oh my god”.

The preceding quotes really highlight this sense of loss. The use of phrases such as: “now it’s just gone!” (Phoebe); “Who am I supposed to talk to?” (John); “What do I do now?” (Angela); “I got upset. I thought “Oh my god”” suggest that the young people were concerned about how they would deal with future issues if they arose. During the interviews the researcher noted that when discussing this particular point in their journey through CAMHS the young people became quite animated and tearful. The interviewer felt that one of the most emotionally salient, and therefore one of the most important aspects of the young people being discharged was not being able to continue to see their practitioner. Angela became particularly emotional at this point and said: “so when it came to it like I was really upset and like obviously, I was so close to them because they’d been like a friend, obviously whilst staying professional”.

The feeling of loss and dependence, discussed by five of the participants, was in stark contrast to the reflections of Julie who had attended CAMHS for just eight sessions. She was offered a follow up session following the completion of these eight sessions which she felt able to decline: “So, like, she did say that if I wanted to, I could go and see her again, but I didn’t feel like I did need to. So it was good”.

For Julie, being offered a set number of sessions at CAMHS appeared to reduce her anxiety about attending mental health services. It also highlights a distinct difference

between the way her sessions were set up compared to the other young people who did have regular weekly meetings for more prolonged periods of time:

“Knowing it was only eight sessions meant that if it wasn’t helping, or if I didn’t like it or whatever it wasn’t forever. So, cos if it had been like just come every week and I’ll like well just do it, it was like how long is this going to take? And, I don’t know if I would have felt like I was getting better because it would just be like going on and I wouldn’t have really felt I was getting anywhere.”

4. I don’t want anyone else!

One issue concerning the therapeutic relationship was that some young people did not want to be referred to AMHS because they were reluctant to begin a therapeutic relationship with a new practitioner. Angela did not believe that she would be able to recreate the relationship she had with her CAMHS practitioner:

“And erm, I wouldn’t want to start again with someone new. Cos erm, I had such a good relationship with the psychologist at the [CAMHS], I just erm don’t think that I’d be able to have that again with someone else. I wouldn’t have wanted it. Not straight away anyway.”

Lisa used emotive language when discussing this and reflected that beginning a new therapeutic relationship would leave her feeling as though she was “betraying” her CAMHS practitioner: “I would have felt, as stupid as this sounds, I would have felt like was betraying them. <laughs> Erm, I don’t know how I would deal with it really?”

Some described not wanting to have to explain their history over again with a new practitioner in AMHS. For example, Phoebe explained: “I couldn’t see the point to be

honest. It would take too long for them to know everything. I couldn't be bothered trying to explain everything again". Similarly, Lisa reflected:

"I'd be, I would be hesitant to start everything again with a new person. I think er, you know, I'm not gonna catch you up on four years am I? And it would be quite different so the fact of starting all of that new, with someone, and now with different issues would be kinda weird"

What will they think of me if I'm an adult with mental health problems?

This superordinate theme pertains to how the young people experienced the transition from what they classed as childhood to adulthood. This included how they thought having mental health difficulties could impact upon their future self. This was both in terms of their own expectations of how they should function as an adult, as well as how they believed others would view them as an adult with a mental health difficulty, and how their future occupations could be affected.

5. They can't find out...

To describe this theme it was important to reflect upon how the young people viewed themselves as adolescents using mental health services as it contextualises their views of being an adult who might need to use mental health services.

Throughout all of the narratives there was a sense that the young people thought that they would be viewed "different" (Phoebe), as "freaks" (Emma and John), or

“odd” (Julie) by other people. There was apprehension with regards to their peers finding out about them attending CAMHS. Some talked about not disclosing their use of mental health services to peers. Lisa described not telling peers as she feared that she would be thought of differently: “And I kept it like that way deliberately, cos I knew that would be it, people’s perceptions would change.”

It appeared that when they did confide in others, the peers they were most likely to tell were those with similar problems, or who had themselves used CAMHS: “the only person who knows I come here is obviously my family. And my best friend, cos she obviously went through it” (Lisa). And: “I couldn’t tell my friends. They er, they er would have thought I was a freak” (Phoebe). Also Julie reflected:

“One of my friends had the exact same problem as me a couple of years ago. So it was good being able to talk to her because she did actually know what it was like. So I then felt like I could talk to her and she wasn’t going to think that cos she knew what it was like”

“well when I was in (CAMHS) I met another girl that was from my school that went for the same reason. So obviously I knew her face from around school, but then I obviously saw her in there so it was, it was good to have someone to relate to for the same reasons.”

(Angela)

This suggests that within teenage social groups mental health difficulties are perceived as stigmatising. Therefore, the young people may only have confided in those who had similar difficulties to avoid the risk of rejection by their peers.

6. New chapter

All of the participants described turning 18 as signifying the beginning of their transition into adulthood. Emma, described this as being a time for her to begin to think about her future:

“But it is like a new start. I think 18 means a lot to a lot of, well to everyone. I definitely think 18 means you know, people begin to think about their adult life. Where they want to be, where they want to go, what they want to do. How they want to live their life and who they want to be. But it’s, when you turn 18, you start thinking right who do I want to be as an adult”.

As the young people spoke about adulthood, they reflected upon the changing expectations on them. For example, Ben spoke about adults needing to be more independent, and more able to deal with problems on their own: “cos I think when you get older you start being more aware of how you should look after yourself and you should get more independent and stuff. You should get more control over stuff.” And similarly, Phoebe reflected: But when you’re 18, you’re an adult. You’ve got to act like an adult. You can’t keep relying on others to sort out your problems. You have to do it on your own.”

For Lisa, moving to university was viewed as an opportunity to be more independent from mental health services:

“Because at that time I thought, I didn’t think I needed to go there, so it was like a new beginning for me. I kept saying like I needed a fresh start at uni, you know, everything new. Cos of all the things that happened that year really and I

thought, ok, maybe it it'll show me that I can cope with it by myself without you know always having someone I can come speak to. So in a way I like I saw it as a challenge" (Lisa)

7. Child versus adult

Woven throughout all of the young people's accounts was the distinct difference they perceived between being a child with a mental health difficulty and an adult with a mental health difficulty. For example, Lisa reflected that parents were seen as being responsible for mental health difficulties in their children. Whereas as an adult the responsibility was hers:

"I reckon it's more well with children I think people mainly blame like their families and how they were brought up and thinking this kids parents screwed up and why's this kid going to counselling. You know, you would think that. You know what have they done kind of thing? Whereas an adult obviously you're independent, you're in control of what you do and its different."

Emma also touched upon this concept, but rather than blame, spoke more in terms of being able to rely upon her parents for support which she felt would not be available to the same degree as an adult:

"being an adult with mental health would be difficult, and I wouldn't have wanted it. And I don't want to ever really have to be that. Because as a child you can just, your parents pick up the pieces. To carry you round, drive you around. If you cry, you're allowed to cry."

The preceding quote highlights how Emma believes it is more acceptable for children to be able to show emotion, suggesting that she believes this is not as acceptable as an adult. This links in with her idea that adults experiencing mental health difficulties are not afforded the same understanding as children: “I wouldn’t get as much sympathy being an adult with mental illness as you get from being a child with a mental illness, or a young person with a mental illness.”

Emma compared how it would be difficult, as an adult, to take time off work if ill. This is in contrast to her experience of being able to take time away from school if she had needed to:

“You have to keep up with er, with your own life. And I don’t think I would ever want to be an adult who had a mental illness, because keeping up with your own life must be horrible. Cos you rely on yourself, you’re much more independent, you have to do things for yourself. Whereas when you’re a teenager if you have a bad day you just don’t go into school, and then if the next day you feel better you go into school. And that’s fine cos everyone takes the odd day off school, you catch up on your work. If you’re an adult you take a day off work, but what if you need a day off the next week. You know no, it would mean, going into adult mental health would mean different things to being in (CAMHS)”

All of the young people also reflected upon how it could be difficult to be an adult with a mental health problem. There seemed to be an underlying belief that if they had a mental health difficulty as they transitioned into adulthood then they would probably have mental health difficulties for the rest of their adult life. Phoebe spoke openly about these concerns:

“God, it’s (AMHS) probably more of a, er, a rest of your life kind of thing. I think kind of CAMHS sees you through your teenage years and then you come to an end of an era, but your adulthood is for the rest of your life. And I don’t think I would have wanted to have been an adult with a mental illness. I don’t think anyone would want to be an adult with a mental illness.”

This belief largely stemmed from how they envisaged that having a mental health difficulty would impact upon their future self, as well as their social and occupational endeavours.

For Lisa, it appeared that being an adult who used mental health services would have been a truly negative experience. This perhaps linked to her not wanting to identify herself as an adult needing support from AMHS: “I know I wouldn’t want to think that I was an adult going to *that* kind of service.” Ben added that attending AMHS could impact on other areas of his adult life. He also reflected that to him it would not “feel right” to use such services once in adulthood: “Well, they might interfere with day to day chores or if anything cropped up, but erm, well I wouldn’t have minded if appointments were like every few months but I, well it just doesn’t feel right coming when I’m in adulthood.”

8. Will I be able to work?

Five of the young people interviewed expressed concern regarding how difficult it could be for them in terms of obtaining and maintaining employment if they had

mental health difficulties. For example, Julie reflected upon how difficult it had been for her to maintain employment as an adolescent when she had been experiencing difficulties. She thought that it would be even more difficult as an adult:

“I had a job for, it was literally for a couple of shifts and that was it and I couldn’t do it. Because I felt so ill. And like if I’d been an adult then, if I couldn’t like if I knew that I couldn’t have a job or I didn’t have anyone to talk to or whatever, that would have been really bad then. And I don’t know if I like, I don’t know what you’d do if you didn’t have support then because that would be really bad.”

Phoebe was also concerned regarding obtaining employment:

“cos er, who would employ me if I er, if I er, If I was mentally ill? No one, I don’t think? Like I couldn’t have time off all the time to go to appointments. What would I tell my boss when I was missing all that time from work?”

This concern was also echoed by Ben. However, he also reflects on how he should be functioning in relation to his peers:

“And erm, it might, it might er interfere with er work and that like if I like when I left college and that, it might erm, well I felt a bit er, what’s the word, er, I wouldn’t feel er right being in AMH when most people my age would be I don’t know working or living on their own somewhere or if they were having a family or something like that I wouldn’t feel right doing adult mental health services.”

Throughout the narratives of the young people there was a distinct sense of concern regarding how other people view them. Lisa believed that there would be negative consequences to disclosing to potential employers that she had experienced, or was

experiencing, mental health difficulties. This was due to her thinking that others viewed mental health difficulties as being a negative thing:

“People see it badly. They see it as a negative. And er, you know, you obviously have to disclose it, disclose that kinda stuff, but you know if I disclose it on like a job application, they’d see it as badly. I’d be like there’s nothing wrong with it, really, I’m not really suffering from anything. It’s normal for people to get upset, and I just needed someone to talk to. But I know they’d see it negatively. I wouldn’t, I’d be hesitant on doing it I guess.”

Interestingly, two of the young people discussed how their own opinions of mental health had changed as a result of experiencing difficulties themselves:

“I think it has changed a lot since I’ve been having that. I probably would have thought the same thing like, if it were like if you were talking to someone with mental health problems you’d be wondering what they would do next. You might think that they were a bit mad or whatever. But just because of that. But now I’ve had it myself I’ve realised that it’s not like that.”

(Julie)

“But obviously, erm when you experience it, you, you... it really is quite different. You don’t think, I think people should realise it’s not a sign that you’re a freak and you need help. It’s more, you now doing something about it the right way.”

(Lisa)

The young peoples references to these changing views is interesting as it suggests that prior to attending CAMHS they too had negative stereotypes of mental health.

Discussion

This qualitative study explored young people's experiences of being discharged from CAMHS without onward referral to AMHS. Six in-depth interviews were conducted with young people who had been discharged from CAMHS in the past year.

All of the young people interviewed felt that establishing a sound therapeutic alliance with their CAMHS practitioner was fundamental in facilitating a positive experience of mental health services. The superordinate theme of "Therapeutic relationship: We're in this together", highlighted the importance for young people of feeling at ease when entering into a therapeutic alliance with an adult; especially when discussing difficulties which they perceived to be embarrassing. This superordinate theme demonstrates that it was important to the young people that what could be thought about as "the building blocks" of a therapeutic relationship were in place, e.g. non-judgemental attitudes, feeling heard and having some control over the therapeutic process (e.g. Lambert & Barley, 2001).

The second sub-theme of "Please don't cut me off just yet" reflects the initial apprehension young people felt with regards to not being discharged from the services as soon as they reached their 18th birthday. They appreciated the flexibility their CAMHS practitioner and indeed the service showed regarding age of discharge. Descriptions of how they would have felt if they had been discharged as soon as they

turned 18 were very emotive, for example feeling “let down” or “angry”. This was largely due to their concerns about their ability to cope with being discharged at a time when there were other competing demands on them such as A-level examinations. Flexibility with regards to discharge is in line with government recommendations (e.g. Department for Children, Schools and Families and Department of Health, 2008) that discharge should be planned and take into consideration the developmental stage of the young person.

In the young people’s narratives, there was ambivalence when it came to being discharged from CAMHS which is reflected in the sub-theme “Am I ready to leave?”. Being discharged was seen as a sign of moving on into adulthood, starting a “new chapter” independent from services. However, this was contrasted with feelings of loss and apprehension regarding the therapeutic sessions ending and whether they would be able to cope on their own. The feelings of loss were more apparent in those young people who had been in CAMHS for an extended period of time. These individuals may have come to see attending CAMHS as normal and had perhaps become over-reliant on the support of their CAMHS practitioner, seeing them as an important member of their support network. At discharge this appeared to impact upon their sense of self-efficacy or belief that they could cope on their own.

Although the therapeutic relationship had been a positive experience for the young people whilst in CAMHS, it also appeared to be a potential barrier for them when

thinking about accessing adult mental health services. Four of the young people identified that one reason that they did not want to be referred into AMHS was because they did not want to start a new therapeutic relationship. These feelings are encompassed in the sub-theme “I don’t want anybody else”. There were several different strands to this, such as the new practitioner not knowing them, they did not want to re-tell their stories, and that they felt that they would be disloyal to their CAMHS practitioner. This raises the question of whether this could be a potential barrier for other young people who *have* been referred to AMHS which could potentially lead to disengagement from mental health services.

The second superordinate theme of “What will they think of me if I’m an adult with a mental health problem?” reflected the young people’s experiences of entering adulthood and the impact that they perceived having a mental health difficulty in adulthood would have on their future. Related to this was the young people’s belief that others would perceive them negatively if they became aware of their difficulties.

The sub-theme “They can’t find out” demonstrates that it was apparent that most of the young people had chosen not to disclose to peers that they were attending CAMHS. This appeared to be due to fearing that their difficulties would not be understood and that they would be stigmatised, being seen as “weird” or “odd”. The exception to this was when they found out peers were also experiencing mental

health difficulties. This concern about how they would be perceived by others appeared to be heightened when they considered how future employers would view their mental health difficulties.

Thus, it appears that the participants wanted to distance themselves from the mental health difficulties that they had experienced as adolescents. This is reflected in the sub-theme of “New chapter”. They spoke about being discharged from CAMHS using phrases such as “drawing a line”, and “graduating from mental health services”. This distancing appeared to be linked to the young people’s concern that if they became adults with mental health difficulties this would impact on the rest of their lives, affecting, for example, their future careers and social relationships.

Erickson (1980) proposed that during the period of early adulthood young people are striving to develop their personal identity. Tanti, Stukas, Hollaran & Foddy (2011) built upon this theory finding that later in adolescence young people become increasingly concerned with their social identity and conforming to their peers’ norms and values. Caelear, Griffiths & Christensen, (2011) reported that young people found that perceived stigma from others was worse than personal stigma which they bestowed upon themselves for having mental health difficulties. Acquiring a label associated with having a mental health difficulty can be viewed as having negative connotations; thus potentially explaining why young people in this study were reluctant to reveal their difficulties to peers (Pinto-Foltz, Logsdon & Myers, 2011;

Elkington et al, 2012). Rusch, Angermeyer & Corrigan (2005) also suggest that transition into adulthood often leads to young people becoming more reliant upon peers whilst they are striving to gain independence from their parents; thus strengthening young people's desire to be part of their peer group which having a known mental health difficulty could jeopardise.

Turning 18 was a significant event for all of the young people interviewed. Moving into adulthood appeared to signify that they were starting the "next chapter" in their lives. The young people within this study spoke about wanting to become more independent, specifically from mental health services, and to "give it a go on their own". However, there was some ambivalence with regards to whether they were ready to do so. This perhaps reflects an internal conflict which has been proposed to occur when young people are unsure whether they are ready to take on the responsibilities of adulthood but nevertheless desire increased independence (Arnett, 2000; Arnett, 2007).

Arnett (1998) proposed that there is a distinct developmental phase, between the ages of 18 and 25 years, where young people move into assuming adult roles and responsibilities. He postulated that there are distinct milestones that signify to young people that they are becoming self-sufficient and therefore moving towards adult status. He proposed that there are criteria which young people strive to attain: the ability to look after themselves, including making independent decisions about their

futures, and working towards achieving financial independence. This perhaps suggests that the participants viewed having mental health problems and using related services as a barrier to achieving independence and attaining future employment (and therefore financial stability), thereby threatening their perceived ability to be able to achieve adult status. Rusch et al (2005) reported that within society there is stigma associated with mental health difficulties which can reduce employability. This societal belief perhaps increased the concerns participants expressed regarding gaining future employment.

The young people perceived a distinct difference between having mental health difficulties as a child versus having similar difficulties as an adult reflected in the sub-theme “Child versus Adult”. This may have reflected beliefs at a societal level about the independence expected of adults that may have been internalised by the young people. There was also a strong narrative about how it is almost “expected” for teenagers to have mental health difficulties, whereas as an adult such difficulties are not so readily acceptable. There were also descriptions about teenagers not having to take “responsibility” for their mental health difficulties; rather, that their difficulties were attributable to their parents. This assuming responsibility for their own health perhaps reflects the movement into adulthood and the perceived expectation of what adults are required to do (e.g. Arnett, 2007).

Dependency upon the therapeutic relationship appeared to be an important finding. Developing a strong therapeutic alliance has been cited as being one of the most important factors for positive therapeutic outcomes, largely because therapy is an inter-personal process (Lambert & Barley, 2001). Building relationships and engaging adolescents in the therapeutic process are especially critical (Oetzel & Scherer, 2005). However, as has been suggested in the young people's narratives it is important that the therapeutic relationship does not move into the realms of dependence. Mallinckrodt (2010) has suggested therapists employ a model of therapeutic distance in their work with clients, reducing dependency, whilst increasing a client's self-efficacy in terms of believing that they possess the resources to deal with their problems, thus reducing the risk of separation anxiety at the point of discharge.

Possible limitations

The participants were recruited from one CAMHS in the West Midlands. Throughout the UK, there may be potential regional differences in the age criteria for continuing within CAMHS (Singh et al, 2008) that may impact on the generalisability of the findings.

There may have been a selection bias in respect of the young people who chose to participate. The pool of potential participants represented those young people who

had opted to be contacted about research at the point of discharge from CAMHS. It may have been that young people who had not had such a positive experience of CAMHS had decided not to opt in. This therefore may skew the findings as the young people interviewed generally expressed satisfaction with the service they received and the therapeutic alliance they developed with their CAMHS practitioner.

A further consideration is that although every effort was made to provide the young people with reassurance that they would not be identifiable by the service as having taken part in the research, concerns about confidentiality may have resulted in the young people seeking to present a positive view of the service.

The researcher also acknowledges that it would have been useful to have recorded the level of agreement between the research team when coding transcripts. It may have also proven beneficial to have asked for and received feedback regarding the suitability of the titles for superordinate and subordinate themes. This may have increased the potential transparency of the content of each theme for readers.

Clinical implications

This research found that young people value having a supportive therapeutic relationship. However, an important consideration was that some of the young people appeared to become somewhat dependent upon their CAMHS practitioners.

It would appear important to help develop young people's support networks outside of the therapeutic relationship. Dependence may explain the reluctance by some young people to move into AMHS. This is an important consideration as it may be that some young people who could have benefitted from therapy in AMHS declined for this reason. Careful monitoring should occur throughout the therapeutic process with therapists adapting styles required to increase young persons' self efficacy.

It may be useful to develop transitional mental health services for young people (Richards & Vostanis, 2004) that span an appropriate age range (e.g. 16-24 years), perhaps based upon service models employed by early intervention for psychosis services (Singh & Fisher, 2005) thus reducing the risks associated with disengagement from services at a crucial developmental stage; and to ensure that transition is not occurring at the same time point as other significant life stresses (e.g. A level examinations).

The young people interviewed spoke about being worried that they would be seen as "odd" or "weird" if their peers discovered that they had mental health problems. Educational workshops delivered at school which normalise mental health difficulties may help to reduce stigma amongst young people. This could have beneficial effects, not only by increasing awareness of mental health difficulties, but by enabling young people to feel better supported and able to disclose such difficulties to their peers. This in turn could lead to less dependence upon practitioners as being the only

source of support and help. This is an area mental health professionals, such as those working in CAMHS, could target by providing consultation to schools on how best to develop and implement such programmes.

Future research

It would be beneficial to conduct further research with young people, perhaps in different geographical regions to increase the knowledge base and identify whether there is consistency in themes across contexts, e.g. urban versus rural. It may also be beneficial to work with CAMHS practitioners exploring their experiences of this transition point with particular emphasis on how they manage dependency issues within their therapeutic relationships with young people. This could potentially lead to positive changes in clinical practice, promoting self efficacy in young people rather than dependency.

Conclusion

The aims of this study were to explore young people's experiences of being discharged from CAMHS without onward referral to AMHS. All six of the young people interviewed described their experiences of CAMHS, and in particular the relationship they built with their CAMHS practitioners as being a positive experience. All interviewed conveyed that they felt that they did not want to be referred on into AMHS. However, rather than this being because they did not need to access services,

it may have been more due to factors such as, not wanting to start a new therapeutic relationship with a new professional; the stigma they perceived may occur for adults with mental health difficulties; the impact that accessing services could have upon their future adult lives e.g. in terms of employment; and them striving to become more independent in line with them striving to achieve adult status.

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Young people's experiences following their discharge from Child and Adolescent Mental Health Services (CAMHS).

Outline

This research was conducted in part fulfilment of the Doctorate in Clinical Psychology at The University of Birmingham. It was completed under the supervision of Dr Biza Stenfert Kroese and with the support of Dr Cara Redmond.

Background

In the United Kingdom, young people who require expert treatment for mental health difficulties often use Child and Adolescent Mental Health Services (CAMHS). These services work with young people up to the age of 18 years, at which point they are either discharged from mental health services, or, if appropriate, referred to Adult Mental Health Services (AMHS). Singh (2009) reported gaps in the evidence base regarding how young people experience this transition point, especially for those who are discharged without onwards referral to adult services. This qualitative study therefore aimed to investigate the experiences of young people who had been discharged from CAMHS without an onward referral to AMHS.

Participants

Six participants (four female, two male) agreed to participate in the study. They were recruited from one CAMHS team in the West Midlands from which they had been discharged within the last year without being referred into AMHS.

Procedure

To gather a rich account of the young people's experiences, Interpretative Phenomenological Analysis (IPA), a qualitative methodological approach, was utilised. A semi-structured interview was constructed according to the procedure outlined within IPA guidelines. The interview schedule comprised of questions designed to elicit detailed narratives from the young people about their experiences of CAMHS and the transition point at which they were discharged from the service without onward referral into AMHS. Transcripts were subsequently analysed according to IPA guidelines, leading to the identification of two superordinate themes, which both comprised of four sub-themes.

Summary of findings

Table 1: Outline of Superordinate themes and sub-themes.

| Superordinate themes | Sub-themes |
|--|---|
| Therapeutic relationship: We're in this together | <ol style="list-style-type: none">1. I don't want to talk to them!2. Please don't cut me off just yet!3. Am I ready to leave?4. I don't want anybody else! |
| What will they think of me if I'm an adult with a mental health problem? | <ol style="list-style-type: none">5. They can't find out!6. New chapter7. Child versus adult8. Will I be able to work? |

The first superordinate theme "*Therapeutic relationship: We're in this together*" focused upon the young people's experiences of entering into a therapeutic relationship with their CAMHS practitioner, how this relationship evolved over time, and how they experienced the ending of this relationship at the point of discharge.

This superordinate theme comprised of four sub themes. The first, *"I don't want to talk to them!"* emerged as the young people interviewed expressed that they were initially anxious about their referral into CAMHS. This worry quickly dissipated and all of the young people described developing positive therapeutic relationships. The second sub-theme *"please don't cut me off just yet!"* related to the concern young people described experiencing when their time in CAMHS was due to come to an end. The third sub-theme *"Am I ready to leave?"* related to the young people's ambivalence regarding whether they were fully recovered from their mental health difficulties and if they would be able to cope with future demands or difficulties without the support of their CAMHS practitioner. They also spoke about the ending of the therapeutic relationship and how this felt like a huge loss to them. The fourth sub-theme *"I don't want anybody else!"* encapsulated the young people's feelings about not wanting to be referred into AMHS upon reaching the upper age limit for CAMHS. Some described not feeling as though they would be able to replicate the therapeutic relationship with a new practitioner in AMHS.

The second superordinate theme: *"What will they think of me if I'm an adult with a mental health problem?"* deals with stigma the young people perceived to be associated with having mental health difficulties and how this could impact upon their future. This superordinate theme comprised of four sub-themes. The first sub theme, *"They can't find out!"* related to the young people believing that they would be judged negatively by others, especially peers, if they were to find out about their mental health difficulties. Thus they described preferring to keep this information to themselves. The second sub-theme *"New chapter"* was developed on the basis of the young people's descriptions of moving into adulthood and being discharged from CAMHS signified a new beginning. The third sub-theme, *"Child versus*

adult” described the young people’s thoughts about their perceived difference between children and adults having mental health difficulties. The young people interviewed expressed that they believed it was more acceptable for children to have a mental health difficulty than it was for adults. Sub-theme four, *“Will I be able to work?”* reflected the young people’s apprehension about whether they would be able to obtain employment if they were to disclose that they had mental health difficulties.

Clinical implications of the research.

Several clinical implications of the research were considered. They include:

- Increase awareness of mental health difficulties in schools to reduce stigma and to enable young people to feel more confident to discuss difficulties they are experiencing and seek appropriate help for such difficulties.
- Increase young people’s awareness of services such as CAMHS and how they operate. This would perhaps reduce young people’s anxiety about attending such services for the first time. It also appeared to be important for practitioners to address potential issues of dependency especially for those young people who are in services for longer periods of time.

In terms of future research, it may be useful to conduct larger scale studies in different geographical locations to investigate whether the themes identified in this study are generalisable to young people across the UK. It may also be useful to conduct research with practitioners to ascertain what their experiences of this transition point are.

Appendix 1

School of Psychology
The University of Birmingham
Edgbaston
Birmingham
B15 2TT

Version 3 November 2011

Dear Sir/Madam,

Re: Participation in research focusing on the point of transfer between Child and Adolescent Mental Health Services and Adult Mental Health Services,

I am writing to inform you about a research project that is taking place to explore young people and their carer's perspectives on leaving Child and Adolescent Mental Health Services (CAMHS). It is hoped that this research will enhance professionals' understanding of how this time is experienced by both young people and their families. To gain this understanding we are hoping to speak to young people and their carers who have recently been discharged from <CAMHS>. We will therefore be contacting people within the next year to discuss this research in more detail and decide if you want to take part. By showing interest in the research, it in no way commits you to participate in any research. If you **would like** to be contacted about this research, then please return the slip below to your therapist.

Kind regards

Michelle Rush

Trainee Clinical Psychologist

I **would like** to be contacted about participating in research relating to my therapy at <CAMHS>.

Please print your name: _____

Sign: _____

Date: _____

Appendix 2

Michelle Rush
Trainee Clinical Psychologist
School of Psychology
The University of Birmingham
Edgbaston
Birmingham
B15 2TT

November 2011 Version 2

Participant Information Sheet

What are the experiences of young-people, who following their discharge from Child and Adolescent Mental Health Services (CAMHS), do not transfer into Adult Mental Health Services (AMHS)?

Thank you for expressing an interest in my research. My name is Michelle Rush and I am a Trainee Clinical Psychologist. I am doing this research study as part of my qualification in Clinical Psychology.

Before you decide if you would like to take part in this study here is some information that may help answer any of the questions you may have about the research study. Please read this information sheet carefully.

Why have I been invited to take part?

You have been asked to take part because you have recently come to the end of your therapy sessions with Child and Adolescent Mental Health Services (CAMHS) but you have not gone on to access Adult Mental Health Services. I would like to ask you some questions about your experience of your sessions with CAMHS coming to an end and what has happened since.

What do I mean by transfer?

Child and Adolescent Mental Health Services (CAMHS) may see young people up to the age of 18, after which they are considered adults and need to access services from Adult Mental Health Services. "Transfer" in this piece of research refers to the time when a young person reaches the upper age limit for Child and Adolescent Mental Health services (CAMHS) and is discharged from the service and does not transfer to

Adult Mental Health Services. For the purpose of this piece of research, we are particularly interested in how young people who do not move into adult mental health services experience this time.

Why is this research important?

So far, only a few research studies have been conducted looking at the point of transfer between Child and Adolescent Mental Health Services and Adult Mental Health Services. There is also a lack of research looking specifically at the experiences of young people who have left CAMHS and have not moved onto Adult Mental Health Services. If we understand more about your experiences, it may be possible to improve what happens in the future for others.

Do I have to take part?

It is entirely up to you to decide whether you wish to take part. If you decide not to take part this will not affect the support you might receive in the future.

What happens next?

If you decide you may want to take part I will contact you to discuss the project and I will answer any questions or concerns that you may have. You can then take some time following this discussion to decide whether you would like to be involved in the study.

What will happen if I agree to take part?

If after the short initial telephone discussion you are still happy to take part, we can arrange to meet have a longer discussion called a research interview. This may last about an hour but this will be flexible depending on how you feel at the time. With your consent I will record the session using a digital voice recorder. Before I start recording I will show you the equipment and how it works. You may stop the recording at any time during the interview.

When you meet with me for the interview I will ask you some questions about what has happened since you have left CAMHS. There are no right or wrong answers to the questions I ask. I am just interested in hearing about your experience.

Does my interview need to be recorded?

Yes. It is important that I can listen to your interview after we have met so I do not miss or forget important things which you tell me. After the interview, I will type it out word by word. This will help me to develop a good understanding of your experiences and our discussion. The recording of your interview will not be listened to by anyone else.

Will anyone know what we talked about?

Everybody taking part in the research will be given a code name so only I will know which interview is yours. During the analysis of the data I may discuss parts of what we talked about with other members of the research team, however only your code name will be used. It may also be that I use your words (a quote from your interview) to describe particular experiences when I am writing up the study. Again, only your code name will be used so only I know if particular quotes came from you.

If during our discussions you tell me that there is a possibility that you are at risk in any way, for example, that you may harm yourself, I would need to discuss this with your GP. I would always tell you if I needed to do this. I would not do this without your knowledge. We will discuss what is meant by “risk” in more detail when we meet.

What happens if I get upset when we are talking or if I have any concerns afterwards?

People get upset for many different reasons. If you find yourself getting upset at any time during the interview just let me know and we will be able to take a break, or, if you prefer, stop the interview. I will also provide you with a list of organizations which you can take away with you to contact if you feel you need any further support following the interview.

Are there any benefits to taking part?

Some people find it helpful to talk about their experiences. It is also important that people who use health services such as CAMHS are able to have the opportunity to feedback how they have found their experiences. Views such as these can be used to improve services in the future.

What will happen if I did not want to carry on with the study?

You have the right to withdraw from the research at any time up until the data analysis begins (which will be two weeks after the interview). I will contact you two weeks after our interview to make sure that you are still happy to be involved in the research study. If you do not want to take part anymore, you do not have to tell me the reason why and withdrawing from the research will not affect your support that you receive now or in the future. If you withdraw from the research study at any point, any information which I have collected such as your name, telephone number or recording of your interview will be destroyed.

Expenses and payments

Your travel expenses to the place where we meet for the interview will be reimbursed. Please provide a valid travel ticket (bus or train). If you travel by car you will be reimbursed 25p per mile you travel. You will also be given a £15.00 Highstreet voucher as a token of appreciation for taking part.

Who has reviewed the study?

The University of Birmingham is involved in the organisation and funding of this study. The study has been reviewed by the School of Psychology to ensure that it meets standards of scientific research and by an NHS Ethics Committee to ensure that it meets important standards of ethical conduct.

Thank you for reading this information. If you are happy to participate or if you have any questions please telephone [REDACTED] and leave a message (please tell the secretary that the message is for Michelle Rush, Trainee Clinical Psychologist) and I will call you back as soon as I can. Alternatively, you can contact me by email: [REDACTED] look forward to meeting with you to discuss the research further.

Yours sincerely, Michelle Rush (Trainee Clinical Psychologist)

Appendix 3

School of Psychology
The University of Birmingham
Edgbaston
Birmingham
B15 2TT

November 2011: Version 2

Consent form

What are the experiences of young-people who following their discharge from Child and Adolescent Mental Health Services (CAMHS) do not transfer into Adult Mental Health Services (AMHS)?

Please read each statement in turn. If you agree with the statement, please place a tick in the box. If you do not understand any of the statements, or have any questions, please discuss this with the researcher.

Once you have completed the form, please sign and date it in the space provided.

I confirm that I have read the information sheet (version 1).

☐

I understand that taking part in the research is entirely voluntary.

☐

I agree that I have been given the opportunity to ask the researcher any questions that I have had about taking part in the research and that these questions were answered satisfactorily.

☐

I understand that I can withdraw from the research at any point before, during or up to two weeks after the interview has taken place without needing to give a reason.

☐

I understand that the interview will be audio-recorded and then transcribed (typed out on the computer) by the researcher.

☐

I understand that the researcher may include quotes (my actual words) from our interview in the write up and possible publication of this research. However, I understand that I will be given a code-name so that nobody will know that the quote came from me.

☐

I understand that other members of the research team might see parts of my interview after it has been transcribed. However, they will never know my real name, only my code name will be used in discussions about the research.

☐

I understand that if the researcher thinks that I am at any risk (for example of harming myself), they will inform my GP. I understand that they will tell me if they are going to do this.

☐

I agree to take part in the above study.

☐

Please print and sign your name in the space below:

Print Name :

Sign Name:

Date:

Appendix 4

Interview Schedule.

Version 1 – July 2011

Opening question:

What is your preferred term for CAMHS/ the service that you received?

(NB: The young persons preferred term will be used in place of CAMHS throughout the interview)

Question 1:

Could you describe your experience of CAMHS to me?

- What were the best things about CAMHS?
- What were the worst things about CAMHS?

Question 2:

Could you tell me how were you told about being discharged from CAMHS/ how did your time in CAMHS come to an end?

- How was being discharged from CAMHS explained to you?
- Do you think being discharged from CAMHS was clearly explained?
- How did you feel about being discharged at that time?
- Do you think your views about being discharged were taken into account?

Question 3:

What did you expect would happen once your time in CAMHS came to an end?

What was the reality?

Question 4:

Did you feel as though you needed further support after you had been discharged from CAMHS?

Yes:

No:

Did you access any other sources of support (family, college counsellor, charities, support groups)?

Do you feel as though you had received enough support from CAMHS and therefore no longer needed additional support?

Did you know how to access future support from health services – where you given an explanation when you were discharged from CAMHS?

Yes:

No:

What information were you given?

How did this leave you feeling?

Question 5:

How were your parents involved in your discharge from CAMHS? (i.e. Where they involved in discussions about your discharge from CAMHS)

How have your parents been involved in your health care since you have been discharged?

How is it to now be in charge of your own health care (rather than parents)?

Question 6:

What do you know about adult mental health services?

- Do you think they would be different from CAMHS? How?

Question 7:

I'm interested in how you felt about not going straight into adult mental health services after you had been discharged from CAMHS.

- What do you think would have been different for you if you had been transferred straight into adult mental health services?

Question 8:

Is there anything that you would like to add?

Is there anything that you thought I might ask you but didn't?

Appendix 5

The following reflexive account outlines some of my own personal experiences which I endeavoured to acknowledge and “bracket off” (Smith, 2004) thus aiming to reduce their influence during interpretation. This project looking at young people’s experiences of transition was of particular interest to me following my past experiences of working as an Assistant Psychologist within CAMHS. During this time I worked with several young people who reached the age cut-off for CAMHS and had been discharged from the service. For some young people and their families this had been a time which had been anxiety provoking for them as they had been unable to access AMHS. This had been for several reasons including their difficulties not being considered severe enough to meet AMHS referral criteria. This had left them feeling unsure as to how they would continue to manage any residual difficulties which were present. They had therefore expressed their anxiety and frustration to me, which, as a therapist had left me feeling as though this transition point could be a negative experience for some. I therefore had to be mindful throughout the development of this research project to reduce the influence of these past experiences upon any aspect of the project. For example, the interview schedule comprised of questions which were open and neutral so as to not influence any responses young people gave. The questions were also triangulated with my supervisor to ensure this neutrality. I also remained mindful of how my past experiences could have influenced my interpretation of the subsequent data set. Following each interview I kept a reflective diary following each interview enabling me to bracket off any biases prior to interpretation. Interpretation of the data was also triangulated with my research supervisor to ensure inter-rater reliability further reducing the possibility that there would be any influenced upon the interpretation.

Appendix 6

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