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**The transition from child and adolescent to adult services
in eating disorders: A qualitative study of service user and
carer perspectives**

and

Clinical Research Portfolio

Volume I

(Volume II bound separately)

Sinead O'Loughlin

**Institute of Health and Well-being
University of Glasgow**

August 2012



**UNIVERSITY
of
GLASGOW**

*Submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology (DClinPsy)*

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Chapter One: Systematic Review

Interventions for carers of people with eating disorders: a systematic review

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***Submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology (DClinPsy)***

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*Prepared in accordance with the requirements for submission to the International Journal of
Eating Disorders (See Appendix 1.1)*

Abstract

Objective: Carers of individuals with eating disorders report high levels of distress and unmet needs. The importance of addressing carers' needs has been increasingly recognised. This review explored the evidence base for educational and skills based interventions for carers of individuals with eating disorders.

Method: A systematic literature search was conducted using Medline, Embase, Psychology and Behavioural Sciences Collection, Psycinfo, CINAHL, Web of Science and pubmed databases to identify relevant studies. Articles were screened against *a priori* inclusion criteria. A narrative synthesis of relevant studies was undertaken.

Results: Eight studies met inclusion criteria. Six studies were rated as “moderate” to “good” methodological quality. Carers interventions were delivered in self-help and workshop formats. The most frequently assessed outcomes were carer distress, experience of caregiving, and level of expressed emotion. Seven studies reported positive outcomes in at least one of these domains. Both delivery formats were comparably effective.

Discussion: The findings from this review provide initial evidence that educational and skills based interventions for carers of individuals with eating disorders reduce carer distress and carer burden, improve negative aspects of the caregiving experiences, and decrease expressed emotion. Further research in this area is needed.

INTRODUCTION

Eating disorders are a group of serious mental illnesses characterised by disordered eating behaviour, and pre-occupation with weight and shape. They include anorexia nervosa (AN), bulimia nervosa (BN), and eating disorders not otherwise specified (EDNOS). Eating disorders most commonly affect young women, with the peak age of onset in mid to late adolescence. Life time prevalence rates for females range from 0.9% to 1.9% for AN, and from 1.5% to 2.9% for BN ^{1,2}. In males, the prevalence rates are 0.3% and 0.5% for AN and BN respectively ¹. Eating disorders are associated with significant co-morbid physical, psychological, social and occupational problems. The outcome for eating disorders is poor. An estimated 20-50% of patients will develop long-term problems ³⁻⁵.

The role of family members in supporting people with serious mental illness has been increasingly recognised, and the value of their contribution is acknowledged within current Mental Health Legislation ^{6,7}. They are often the first to recognise difficulties, encourage their loved ones to seek treatment, and provide day to day support. Family members are considered to play a key role in recovery, and it is recommended by the Academy for Eating Disorders, amongst others, that they should be routinely involved in the treatment of most young people with eating disorders ⁸⁻¹⁰. Furthermore, the National Institute for Clinical Excellence Guidelines for Eating Disorders advocate that most people with AN and BN should receive treatment on an outpatient basis⁸. These factors place family members at the fore of caregiving in eating disorders.

Living with and providing care to someone with an eating disorder is associated with poorer mental health, poorer physical well-being and lowered quality of life ¹¹⁻¹⁶. Clinically significant rates of anxiety and depression have been identified in over

50% of parents of people with AN, and nearly 60% of carers of people with AN or BN report feeling depressed and burnt out ^{14,15}. Carers report high levels of unmet needs which contribute to their distress ^{14,17}. The converging evidence from quantitative and qualitative research in this area attests that, although carers are eager to support their loved ones, they feel that they have insufficient knowledge and skills to fulfil this role. Carers have highlighted the need for more information about diagnosis, treatment and relapse, and practical and emotional support to help in dealing with the eating disorder ^{14,17-21}. Counselling and support by professionals, family sessions and psycho-education were the interventions that carers rated highest on their list of needs ¹⁴. The difficulties many carers experience accessing support from professionals are compounded by depleted social support networks. Carers report that support from family and friends can be impeded by stigma and a lack of understanding of eating disorders. Consequently, carers often feel socially isolated ^{14,18,22}.

High levels of Expressed Emotion (EE) have also been identified in carers of people with eating disorders ¹⁶. EE reflects high levels of critical, hostile, or emotionally over-involved attitudes. Historically, it was held that such patterns of family interaction were a primary cause of eating disorders¹⁰. However, current opinion holds that such characteristics are the result of living in a family system affected by a serious illness, which is associated with distressing clinical symptoms and disturbed behaviours. In this context conflict and over-involvement may be construed as more or less adaptive coping strategies ^{23,24}. Misperceptions about the causes, consequences and outcomes of the illness have also been found to contribute to critical and overly-involved response styles ²⁵. It is widely acknowledged that family interactions high in EE are associated with poorer clinical outcomes in

mental illness²⁶. In AN, high EE, maternal criticism in particular, has been found to impact outcomes and response to treatment^{23,27}. Indeed, it has been hypothesised that high EE is one of four key maintaining mechanisms in AN²⁸.

Given the potential gravity of eating disorders, the high levels of distress and unmet needs reported by carers, and the perpetuating role that carer response styles may have in the illness, the importance of addressing carers' needs and providing them with the support they require is becoming increasingly recognised by professionals^{14–16}. If carers receive the practical and emotional support they require, and feel that their contribution is valued, it seems likely that this will not only serve to decrease their distress but will also enable them to be more effective in their caregiving role. This is in line with the vision laid out within recent Carers Strategies from the British and Scottish Governments^{29,30}.

A number of recent intervention studies have sought to address the needs of caregivers in eating disorders. No systematic reviews of the evidence for carers interventions in the area of eating disorders have been identified. This is an area with a developing evidence base and it is, therefore, timely to investigate the clinical effectiveness of such interventions. This review aims to explore the evidence base for carers interventions in the area of eating disorders, to summarise the primary findings and to report on the clinical effectiveness of these interventions. In addition, any gaps in the literature and implications for further research will be identified.

METHOD

Search Strategy

A systematic literature search was conducted in January 2012 using the OVID, EBSCO and Web of Knowledge on-line interfaces to identify relevant articles from the following databases: Medline, Embase, Psychology and Behavioural Sciences Collection, Psychinfo, CINAHL, Web of Science. An additional search was completed using pubmed. Subject heading searches and keyword searches using the following terms:

("Eating disorders" OR "Anorexia Nervosa" OR "Bulimia Nervosa")

AND

("caregivers" OR "carer" OR "family")

AND

("intervention studies" OR "intervention" OR "clinical trial" OR "trial" OR "study" OR "patient education" OR "psycho-education" OR "psychoeducation" OR "self-help groups" OR "groups" OR "information sessions")

AND

("psychological stress" OR "stress" OR "depression" OR "anxiety" OR "expressed emotion" OR "burden" OR "well-being" OR "wellbeing" OR "symptoms" OR "functioning")

Truncating was used to ensure identification of relevant terms where word endings may differ e.g. plural or adjectives. The search was limited to English language and humans. No date range limit was applied, so this extended to the complete range covered by each database.

In addition to searching electronic databases a hand search of the following journals was undertaken (covering the period January 2000-January 2012): International Journal of Eating Disorders, European Eating Disorder Review, Eating Disorders: The Journal of Treatment & Prevention. This search confirmed the sensitivity of the database search, as it established that all eligible studies had been identified. The reference lists of full-text articles retrieved using the above search strategy were hand searched to identify other potentially relevant studies.

Inclusion Criteria

All articles were screened against inclusion criteria, as detailed below in Table 1. Studies that did not meet the criteria were excluded from the review.

Table 1: Inclusion Criteria

Category	Criteria
<i>Publications</i>	Journal Articles English Language
<i>Study Design</i>	Randomised Controlled Trials (RCTs). As it was not anticipated that there would be sufficient numbers of RCTs, quasi-experimental studies were also considered. This included non-randomised controlled studies, before-and-after-studies and interrupted time series studies.
<i>Participants</i>	Participants were carers of individuals with eating disorders (anorexia nervosa; bulimia nervosa; eating disorder not otherwise specified). This included relatives, partners or friends.
<i>Interventions</i>	Any skills based or educational intervention for carers of people with eating disorders.
<i>Outcome</i>	A minimum of one outcome measure in the following areas: level of expressed emotion, psychosocial functioning, quality of life or experience of caregiving.
<i>Comparator</i>	All comparators were considered. These included treatment as usual, an alternative intervention, or before and after comparisons in the same sample.

Data Collection and Quality Assessment

A standardised data extraction form was developed based on guidance from the Centre for Reviews and Dissemination (CRD) ³¹. Data items included study characteristics, participant characteristics, intervention, setting, outcome measures and results. This data was extracted from all articles by one researcher (SOL).

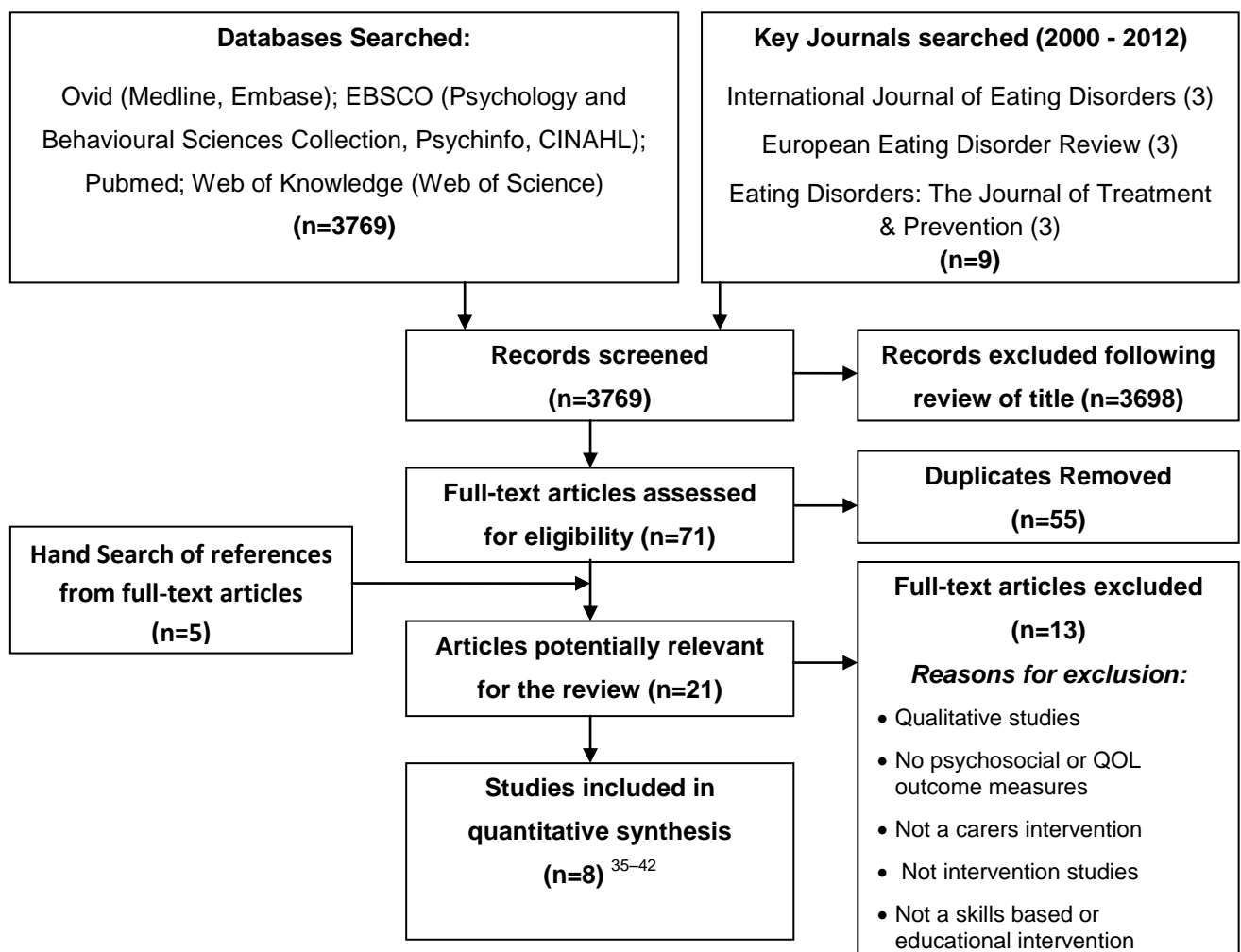
A modified version of the Downs and Black ³² checklist for assessment of methodological quality of both randomised and non-randomised studies of health care interventions was selected for assessment of all included studies (see Appendix 1.2). This checklist was identified by Deeks et al. ³³ as one of the best assessment tools for systematic reviews of non-randomised studies, and is also recommended within the CRD's guidance on undertaking systematic reviews in health care ³¹. It contains 27 items assessing quality across four domains: standard of reporting, external validity, internal validity and power. A percentage rating was calculated for each paper and the following rule of thumb was applied to describe the quality of the study 'Good' (> 75%), 'Moderate' (50-75%) or 'Poor' (<50%). One researcher (SOL) rated all papers and 75% of these were also rated by a second researcher, a Doctorate of Clinical Psychology Trainee who was independent of the study. Agreement rates between researchers were 87% and any disagreement was resolved by discussion.

It was envisaged that there would not be a large number of high-quality RCT design studies in this area. As meta-analysis based on small trials can be considered unreliable ³⁴, it was decided to undertake a narrative synthesis ³¹.

RESULTS

The search strategy identified 3,769 articles. It was identified that 3,753 articles were not relevant to the current review, excluded on the basis of titles or duplication. Abstracts and full-text of the remaining papers were reviewed using the full inclusion criteria. This resulted in the exclusion of 13 further papers (see Appendix 1.3). A total of 8 studies fulfilled criteria for inclusion in this review: Gísladóttir & Svavarsdóttir ³⁵, Goddard et al. ³⁶, Grover et al. ³⁷, Grover et al. ³⁸, Sepulveda et al. ³⁹, Sepulveda et al. ⁴⁰, Sepulveda et al. ⁴¹, Uehara et al. ⁴² The study selection process is illustrated below (Figure 1).

Figure 1: Flow diagram of study selection process



Description of Studies

A summary of all studies included in this review is provided in Table 3 (page 24).

Study design

Of the eight included studies only one was a RCT³⁷. In this study, participants in the control condition were able to access existing support services provided by Beat, a UK based Eating Disorders Charity. A second study³⁶ outlined that participants were randomised to one of two active interventions, self-help or guided self-help. However, coaching sessions provided in the guided self-help condition were not found to have any additional benefit and both groups were combined for the main analyses. The six non-randomised studies all utilised before and after research designs^{35,38–42}. Five of these studies were reported as preliminary studies^{35,42} or acceptability and feasibility studies^{38,40,41}.

Sample sizes ranged from 16 to 153 across studies. Power calculations were only reported in two studies, calculated with 80% power to detect clinically significant differences between comparison groups^{36,37}. Both studies recruited a sufficient number of participants at baseline, however, drop-out rates reduced sample sizes below the required numbers for analysis at post-intervention³⁷ and follow-up^{36,37}.

Sample Characteristics

Six studies were conducted in the United Kingdom (UK)^{36–41}. All six UK based studies were undertaken by the Institute of Psychiatry, King's College London. The two remaining studies were carried out in Japan⁴² and Iceland³⁵. All participants were volunteers recruited from Mental Health Services^{35,41,42}, Eating Disorder Services^{35,38–41}, Eating Disorder Charities^{38–40}, carers association/groups⁴¹, volunteer databases³⁸ or advertisements^{36,38–40}.

The eligibility criteria for carers varied across studies. Three studies included only family carers ^{35,39,42}, three studies used a broader definition of carers that included relatives, partners or friends ^{36–38}, while the remaining two studies specified that carers had to be living with or directly involved in the care of the person with an eating disorder ^{40,41}. Six studies included carers of people with AN, BN and EDNOS ^{35,36,39–42}. The final two studies solely included carers of people with AN ^{37,38}.

Carers

Across all studies the majority of carers were parents of individuals with eating disorders. Where the parental role was further specified, mothers represented 50-75% of the entire sample ^{36–38,42}. Spouses, partners, siblings, children and grandparents were represented to a lesser extent. The mean age of carers ranged from 48.2 to 53.3 years, where this was reported ^{36–41}.

Six studies provided information about carers' educational attainment. Two UK based studies reported rates of carers with Diploma, University or Post-Graduate University Degrees at 75% or above ^{37,38}. This is higher than the average population rates for the UK ⁴³, indicating that these studies probably involved participants of a higher socioeconomic status. Two further UK based studies reported rates of 50-59%, roughly representing population levels ^{40,41}. The final two studies ^{35,39} reported attainment rates of carers with University Degrees, or equivalent, below the population rates for their respective countries ^{43,44}, indicating that these studies may have involved participants of a lower socioeconomic status.

Five studies reported the employment status of participants, including four UK based studies ^{36,38–40} and one Icelandic study ³⁵. Of the UK based studies, three ^{36,39,40} reported rates of full-time or part-time in line with employment rates reported

by the Office of National Statistics ⁴⁵. The final UK study reported employment rates approximately 13% below the national average, despite carers in this study having higher levels of education ³⁸. Gísladóttir & Svavarsdóttir ³⁵ reported rates of full-time or part-time employment as 95%, however, national rates for Iceland were unobtainable.

All studies provided information about the level of contact between the carer and service user. A high proportion of carers were reported to be living with the individual they care for. Two studies reported rates of 100% ^{35,42}, while a further five studies reported rates of 71 to 78% ^{36,38–41}. Where the amount of contact was further specified, 58 to 62% of carers reported more than 21 hours per week direct contact with the person they care for ^{36,39,40}. The final study reported that 78% of carers had daily contact with the individual they cared for ³⁸.

Service Users

The characteristics of individuals cared for by the research participants were described in all studies. The mean age of service users ranged from 17.2 to 28 years. Six studies reported the gender of service users. Of these, two studies consisted of all female samples ^{35,40} and the remaining studies reported small numbers of male participants, representing only 3-7% of samples ^{36,39,41,42}. The majority of studies reported a high proportion of service users diagnosed with AN (69-80%). BN was the second most common diagnosis followed by EDNOS. Only one study reported a differing pattern within their sample, with 57% of service users diagnosed with BN ³⁵. Five studies provided information about the duration of illness ^{36–39,42}. This ranged from 4 to 7.07 years.

Intervention

A range of interventions were represented across the eight studies. These can be categorised into two main approaches: self-help interventions ^{36–38,41} and group or workshop interventions ^{35,39,40,42}.

Self-help Interventions

Self-help interventions were delivered in a variety of formats: DVD and manual ^{36,41}, web-based ³⁷ or workbook ³⁸. Clinician support was provided in all self-help interventions, with the exception of one intervention group within the Goddard et al. study ³⁶. Participants in the DVD interventions were offered three telephone coaching sessions of thirty to forty minutes each ^{36,41}, while participants in the web-based and workbook interventions were provided with telephone or e-mail guidance sessions of up to 20 minutes per week while completing modules ^{37,38}. The intervention period ranged from 6 weeks to 16 weeks across three studies ^{36,37,41}. The remaining study did not have a pre-defined intervention period ³⁸.

Group or Workshop Interventions

In the group or workshop interventions, the number of sessions ranged from 4 to 6. The length of sessions was reported in three studies, this was two hours ^{39,40,42}. Sessions were delivered on a weekly ³⁵, twice-monthly ^{39,40} or monthly basis ⁴². Two of the workshops were based on the same model of intervention ^{39,40} and readers were directed to a paper describing the full details of this intervention ⁴⁶. This information will be incorporated in the discussion on intervention content.

Intervention Content

A full description of intervention content is provided in Appendix 1.4. All studies

reported providing education about eating disorders and the factors that maintain eating disorders. There were other common aspects across the interventions which can be summarised as follows:

Helping carers to understand and meet their own needs: This was explicitly reported in six interventions ^{35–40}. Specific strategies included stress-management skills ³⁶, distraction and mindfulness ^{39,40}, and encouraging carers to take respite ³⁵.

Recognising the role of interpersonal interactions in eating disorders: Six studies described helping carers to recognise and reflect on how their emotional and behavioural reactions to their loved one's symptoms may play a role in maintaining them ^{36–41}. The process of helping carers to develop more balanced, warm, supportive and encouraging responses was referred to within four studies ^{35,39–41}.

Developing knowledge and skills to support behavioural change: The content of five interventions focused on supporting behavioural change ^{36,38–41}. Principles of the Transtheoretical Model (TTM) and Motivational Interviewing (MI) were used to help carers change their own behaviour, enhance positive communication and then facilitate change in the person they care for. These principles were also incorporated in two Cognitive Behavioural Therapy (CBT) based interventions to enhance communication skills and understanding of stages of change ^{37,38}.

Understanding the function of problematic behaviours: Five studies reported helping carers to understanding the function of problematic behaviours, such as obsessive compulsive behaviours, over-exercise and purging, and how to support the person with the eating disorder to stop these ^{37–41}. The use of functional behavioural analysis to examine the antecedents and consequences of problematic behaviour was described in two studies ^{39–41}.

Externalising the Eating Disorder: Four studies described using externalising techniques to help carers separate the eating disorder symptoms from their loved one^{35,39,40,42}.

Developing skills in problem solving and goal setting: Four studies reported that problem solving strategies and goal setting were incorporated within their interventions^{36,38–40}. One additional study did not explicitly report using problem solving and goal setting³⁷, however, these are core elements of The Five-Areas Approach to CBT⁴⁷ on which the intervention was based.

Therapists/Coaches

Seven studies provided details about those involved in delivering interventions^{35–41}. The majority of interventions were delivered by mental health professionals. With the exception of one study^{36–41}, all professionals were described as having expertise working with individuals with eating disorders, and skills in CBT, MI or group dynamics.

Expert carers supported the delivery of one group intervention³⁹ and acted as coaches in two self-help interventions^{36,41}. These were individuals who had personal experience of caring for a family member with an eating disorder and had been trained in the delivery of groups and/or in MI.

Supervision arrangements were only reported in the self-help intervention studies^{36–38,41}. Additional steps to monitor therapist adherence to treatment, such as recording guidance sessions, were reported in three of these studies^{37,38,41}. Issues of therapist adherence to protocol and therapist competence were not reported in any of the work-shop based interventions^{35,39,40,42}.

Outcome Measures

Self-report measures were utilised to assess outcomes in all eight studies. Three studies also included clinician-rated measures ^{38,39,42}. The main domains assessed were carer distress, experience of caregiving, level of EE, family functioning and severity of eating disorder symptoms. A total of seventeen outcome measures ^{48–62} were reported across the eight studies. However, there was considerable overlap in the outcome measures used within the UK based studies ^{36–41}. A full description of the outcome measures and the studies they were used within is provided in Appendix 1.5.

Quality of Included Studies

Two studies were rated as good quality, four studies were rated as moderate quality and two were rated as poor quality. A summary of the quality ratings for all studies included in this review is provided in Table 2.

Table 2: Quality rating of studies included in systematic review.

Study	Total out of 27	% Rating	Overall Rating
Goddard et al. ³⁶	23	85%	Good
Grover et al. ³⁷	22	81%	Good
Grover et al. ³⁸	16	59%	Moderate
Sepulveda et al. ³⁹	16	59%	Moderate
Sepulveda et al. ⁴⁰	16	59%	Moderate
Gísladóttir et al. ³⁵	14	52%	Moderate
Uehara et al. ⁴²	13	48%	Poor
Sepulveda et al. ⁴¹	12	44%	Poor

Reporting

The quality of reporting was generally high. Objectives, outcomes, interventions and baseline demographic and clinical characteristics were clearly described in all

studies. With the exception of Sepulveda et al.³⁹, all studies reported eligibility criteria. Simple outcome data and estimates of random variability in the data were reported for main outcomes in six studies^{35,36,38–40,42}. Grover et al.³⁷ did not report simple outcome data but did provide estimates of random variability, while neither were reported by Sepulveda et al.⁴¹

External Validity

As all studies relied on volunteers, the samples cannot be said to truly represent the population of carers supporting people with eating disorders. The number of participants who were invited or expressed interest in participating, relative to the number who agreed to participate, was only reported in three studies^{36–38}. Opt-in rates of between 86 and 95% were reported in these studies.

Four studies used self-help interventions which could be delivered through distance learning^{36–38,41}. As this could be incorporated into standard treatment approaches for eating disorders, these interventions were considered to be representative of treatment that the majority of carers could receive. This enhances the generalisability of findings from these studies. One study provided treatment in a setting that was not considered to be representative of standard treatment³⁵, and a further three studies did not provide enough information to determine representativeness^{39,40,42}.

Internal Validity

Only two studies randomised participants to intervention groups^{36,37}. Both of these studies adequately reported randomisation procedures, using computer-generated randomisation codes for block randomisation³⁶ and individual randomisation³⁷. Procedures for concealing treatment allocation from researchers

until completion of recruitment were described in both studies. Due to the nature of psychological interventions, participants could not be blinded to treatment in any of the eight studies. Attempts to blind assessors were reported in only three studies. This was accomplished using postal return of assessment measures ³⁶, enlisting another clinician to inform participants of randomisation thus allowing the assessor to remain blind ³⁷, and blinding independent assessors to the timing of assessments i.e. before or after intervention ³⁹.

A variety of statistical tests were employed across studies including Paired t-tests, ANOVA, MANOVA and their non-parametric equivalents, and Linear Mixed Methods Models. The statistical tests used to assess the main outcomes in all studies were considered to be appropriate. Where data was identified as not being normally distributed, data was transformed ³⁷ or non-parametric tests were used ^{40,41}. Unfortunately, only two studies clearly reported adjusting for multiple comparisons, both applying Bonferroni corrections ^{39,40}. However, a further three studies ^{36–38} used Linear Mixed Methods Models in their analysis, which are regarded as producing a lower risk of Type-I error ⁶³. It was considered that all studies differentiated primary pre-planned analyses from any retrospective exploratory analysis in their results.

Compliance with intervention will first be considered for those studies employing self-help models. Three studies reported high rates of compliance amongst participants who completed the interventions. Grover et al. ³⁷ reported that 90% of participants completed all modules in their web-based study and 91% availed of clinician support. Sepulveda et al. ⁴¹ reported that each of the five DVD's in their intervention was watched by 91 to 100% of participants. Finally, Goddard et al. ³⁶ reported that the mean proportion of materials completed was 8.1 and 9.2, for their self-help only and guided self-help conditions respectively, on a scale where 10 is

the highest score. Grover et al.³⁸ did not provide sufficient information to determine compliance. For the workshop interventions, attendance rates for completers were reported in three studies: Sepulveda et al.^{39,40} reported that 94.3% and 92.6% of participants attended 4 or more workshops respectively, while Gísladóttir & Svavarsdóttir³⁵ reported that 87.5% of participants attended all sessions.

Follow-up times were equivalent for all participants in six of the studies^{35,37,39–42}. Goddard et al.³⁶ reported a shorter baseline assessment period for a proportion of their participants but this was accounted for in their analyses. Grover et al.³⁸ reported wide variation in the time taken to complete their intervention, however, post-intervention and follow-up assessment points were consistent across participants.

The number of participants lost to follow-up was reported in all studies. Attrition rates at post-intervention ranged from 3.0 to 28.3% and at follow-up ranged from 8.6 to 39.3% in intervention groups. Grover et al.³⁷ was the only study to employ a control group, the attrition rate for this group was 30.0% post intervention and 43.3% at follow-up. Reasons for loss to follow-up were reported in five studies^{35,38–41}. These included unforeseen personal circumstances, work commitments, family difficulties, insufficient time and service user objections to carer participation. The remaining studies failed to report clear reasons for attrition^{36,37,42}. However, Grover et al.³⁷, who reported the highest rates of attrition, hypothesised that this was due to the minimal support provided in their web-based intervention and lack of personal contact in their control condition.

Intention to treat analysis was not reported in any of the studies. However, three studies employed Missing at Random (MAR) assumptions to account for missing data^{36–38}. The remaining studies used per protocol analysis^{35,39–42}.

Findings

Carer distress

Reductions in carer distress were reported in two good quality studies ^{36,37} and three moderate quality studies ^{38–40}. It was identified as the primary outcome measure within four of these studies ^{36–38,40}. Grover et al. ³⁷ reported a greater decrease in Hospital Anxiety and Depression Scale (HADS) ⁴⁸ total anxiety and depression scores for participants in their web-based intervention group than controls. This difference was statistically significant post-intervention but was not maintained at follow-up. Goddard et al. ³⁶ reported a statistically significant reduction between baseline and post-intervention on HADS total scores and General Health Questionnaire (GHQ) ⁴⁹ scores in their DVD based intervention. However, only the reduction in HADS total scores remained significant at follow up. Grover et al. ³⁸ reported significant reductions in HADS total scores between baseline and post-intervention, and at follow-up in their workbook based intervention with medium to large effect sizes. Finally, two studies by Sepulveda et al. ^{39,40} that employed the same workshop model reported significant reductions in GHQ scores post-intervention, which were maintained at follow up. Small to medium effect sizes were reported in both studies.

Caregiving experience

Improvements in caregiving experience were reported in one good quality study ³⁶ and three moderate quality studies ^{38–40}. Experience of Care Giving Inventory (ECI) ⁵¹ was the most commonly reported measure. Significant reductions between baseline and post-intervention were reported on the negative scale of the ECI in self-help ^{36,38} and workshop based interventions ^{39,40}, with effect sizes ranging from small

to medium. The reductions remained significant at follow up in two of the studies^{38,40} and a further study³⁹ reported that post-intervention reductions on three subscales within the negative scale, were maintained at follow up. Conversely, Grover et al.³⁷ failed to find any significant effects although there was a greater reduction in ECI negative scale scores in their intervention group. A significant increase on the positive scale of the ECI post-intervention was also reported in one study³⁸, although scores returned to baseline levels at follow-up. Small effect sizes were reported.

Improvements in caregiving burden were reported in one good quality study³⁶ and two moderate quality studies^{38,40}. Significant reductions in scores on The Eating Disorders Symptoms Impact Scale (EDSIS)⁵² between baseline and post-intervention were reported in two self-help interventions^{36,38}. One study reported a further significant decrease at follow-up, with a small to medium effect size³⁸. Sepulveda et al.⁴⁰ also reported a significant reduction in EDSIS scores between baseline and follow-up in their workshop intervention, with a medium effect size. Conversely, Grover et al.³⁷ failed to find any significant effects although there was a greater reduction in EDSIS scores in the intervention group. Finally, Goddard et al.³⁶ reported a significant increase in caregiving self-efficacy between baseline and post-intervention.

Level of expressed emotion

Reductions in EE were reported in one good quality study³⁶, two moderate quality studies^{38,39} and one poor quality study⁴². Two self-help interventions^{36,38} reported significant decreases in EE between baseline and post-intervention on the The Family Questionnaire (FQ)⁵⁶ and Level of Expressed Emotion Scale (LEE)⁵⁵ respectively. Goddard et al.³⁶ reported a further significant decrease between post-

intervention and follow-up, while Grover et al.³⁸ reported a significant reduction between baseline and follow-up, with a large effect size. However, Grover et al.³⁸ outlined that these reductions did not significantly change the rates of carers categorised as high in EE on LEE and they reported similar findings on the Five Minute Speech Sample (FMSS)⁵⁴. In contrast, Sepulveda et al.³⁹ and Uehara et al.⁴² reported significant reductions in the proportion of carers rated as high in EE on the FMSS after their workshop interventions, although Sepulveda et al.³⁹ identified a slight increase in rates at follow-up in the study.

Family Functioning

The extent of accommodation and enabling behaviours within the family were assessed in two studies of good quality^{36,37}, with equivocal results. Goddard et al.³⁶ reported a significant decrease in accommodation and enabling behaviours between baseline and post-intervention, while Grover et al.³⁷ failed to find any significant effects although there was a greater reduction in scores on the Accommodation & Enabling Scale for Eating Disorders⁵⁸ in the intervention group. A final study by Uehara et al.⁴² looked at cohesion and adaptability within the family. They reported significant improvements in both aspects of family functioning between baseline and post-intervention with large effect sizes.

Service User Outcomes

Service user outcomes were assessed in one good quality study³⁶, one moderate quality study³⁵ and one poor quality study⁴². Goddard et al.³⁶ found that carers reported a significant reduction in eating disorder symptoms between baseline, post-intervention and follow-up. They also found that carers reported significant improvements in service user functioning between baseline and follow-up.

Gísladóttir & Svavarsdóttir ³⁵, found that carers reported a reduction in eating disorder symptoms between baseline and post-intervention on the Anorectic behaviour observation scale questionnaire⁶¹, with a small to medium effect size. Similar findings were reported by Uehara et al. ⁴², however, this finding was only significant for three of the subscales. Uehara et al. ⁴² also reported improvements in service user functioning on a carer rated measure, but they did not find any significant change on a clinician rated measure of eating disorder symptoms.

Table 3: Summary of studies included in systematic review of carers interventions in eating disorders

Study	Design	Intervention	Sample Size	Service User(SU) Characteristics	Treatment Length	Completed Treatment (N)	Outcome Measures	Main Findings <i>where effect size has been calculated for this review this is denoted d</i> <i>Estimated reduction (ER)</i> <i>Estimated increase (EI)</i> <i>*($p<.05$) **($p<.001$)</i>
Country		Profession of clinicians involved in Intervention	Relationship to Service User	Diagnosis	Assessment points	Followed-up (N)		
Quality Rating								
Abbreviations: Eating Disorder (ED); Anorexia Nervosa (AN); Bulimia Nervosa (BN); Eating Disorder Not Otherwise Specified (EDNOS); Carers (C); Service Users (SU); Professional (P); Family Functioning (FF); Expressed Emotion (EE); Follow-Up (FU). Abbreviations for outcome measures listed at end of table.								
Goddard et al. ³⁶	Before & After study	Self-help intervention DVD and workbook Self-help (ECHO) vs Guided self-help (ECHOc)	N=153 Carers	N=153 SU N= 146 Female N= 7 Male Age ($M=20.85$)	6 weeks	N= 80 ECHO N=73ECHOc combined for main analysis	HADS GHQ ECI EDSIS FQ CSE AESED GEDF EatBeh	<i>Decreased in C distress</i> HADS Total: $T1>T2=T3^{**}$ ($E.R$: -4.8, CI -6.3 to -3.4) GHQ: $T1>T2$ (ER : -2.7, $p=0.001$, CI -4.2 to -1.1) <i>Improvements in aspects of caregiving</i> ECI-negative: $T1>T2^{**}$ (ER : -13.4, CI -19.4 to -7.5) CSE: $T1<T2^{**}$ ($E.I$: 9.0; CI 4.6 to 13.5) EDSIS: $T1>T2$ ($E.R$: -4.5, $P=0.002$; CI -7.4 to -1.7) <i>Decrease in EE</i> FQ: $T1>T2>T3^{**}$ ($E.R$: -4.3, CI -6.2 to -2.4) <i>Improvements in FF</i> AESED: $T1>T2^{**}$ (ER :-9.1, CI -13.4 to 4.8) <i>Improvements in ED symptoms- C report</i> GEDF: $T1<T2<T3^{**}$ ($E.I$: 6.8, CI 3.8 to 9.8) EatBeh: $T1>T2^{**}$ ($E.R$: -0.8, CI -1.2 to -0.5)
UK Good		Guidance was provided by a clinical nurse specialist in ED, a clinical psychologist and a carer.	N=130 Mothers N=9 Fathers N=8 Spouse/ Partner N= 2 Child N= 4 Other	N=122 AN N= 12 BN N= 5 EDNOS N = 3 Unknown	Baseline Pre-treatment Post-treatment 3 month FU	T0 N=153 T1 N=80 ECHO T1 N=73ECHOc T2 N=63 ECHO T2 N=57ECHOc T3 N=61 ECHO T3 N=52ECHOc		

Table 3: Summary of studies included in systematic review of carers interventions in eating disorders (continued)

Grover et al. 37	RCT	Self-help intervention 8 web-based modules and a manual Self-help (OAO) vs Beat support (Control)	N=67 Carers	N=63 SU Age ($M=20.4$, $SD=6.2$ range=12-44)	4 months	N= 33 OAO N= 30 Control	HADS ECI EDSIS LEE AESED	Decreased in C distress HADS Total: OAO greater decrease than Control $T1>T2^{**}$ ($E.R$ -3.8, CI -7.3 to -0.3) Not significant at T3
UK Good		Guidance was provided by a psychologist and a psychotherapist with ED expertise	N=50 Mothers N=5 Fathers N=5 Spouse/ Partner N= 3 Other	N=49 AN N=13 EDNOS N= 1 Unknown	Pre-treatment Post-treatment 6 months FU	T1 N=33 OAO T1 N=30 Control T2 N=24 OAO T2 N=21 Control T3 N=20 OAO T3 N=17 Control		
Grover et al. 38	Before & after study	Self-help intervention 9 interactive workbooks	N= 27 Carers.	N= 27 SU Age ($M=28$, $SD=9.45$, range=14-55)	($M=135$ days, range=61-286 days)	N= 27 Carers	HADS ECI EDSIS LEE FMSS SPRI-R	Decreased in C distress HADS- total: ($F=9.680$, $p=0.001$) $T1>T2$ ($p=.002$, $d=.69$) $T1>T3$ ($p<.001$, $d=.78$) Improvements in aspects of caregiving ECI-negative: ($F=9.709$, $p=0.002$) $T1>T2^{**}$ ($d=.33$) $T1>T3$ ($p=.03$, $d=.44$) ECI-positive: ($F=6.161$, $p=0.01$) $T1<T2$ ($p=.02$, $d=.41$) $T2>T3$ ($p=.004$, $d=.38$) EDSIS: ($F=8.871$, $p=0.003$) $T1>T2$ ($p=.03$, $d=.22$) $T1>T3$ ($p=.002$, $d=.6$) $T2>T3$ ($p=.03$, $d=.4$) Decrease in EE LEE: ($F=11.843$, $p=0.001$) $T1>T2$ ($p=.04$, $d=.49$) $T1>T3$ ($p=.001$, $d=.8$)
UK Moderate		Guidance was provided by a trained CBT practitioner with ED expertise.	N=17Mothers N=3 Fathers N=6 Spouse/ Partner N= 1 Sibling	N=24 AN N=2 EDNOS N= 1 Recovered	Pre-treatment Post-treatment 10-12 weekFU	T1 N=27 T2 N=22 T3 N=18		

Table 3: Summary of studies included in systematic review of carers interventions in eating disorders (continued)

Sepulveda et al. ³⁹	Before & after study	<u>Workshop Intervention:</u> 6 workshops	N=68 Carers	N=46 SU N= 43 Female N= 3 Male Age ($M=21.5$, $SD=5.3$, range= 9-43)	3 months	N= 63 Carers N=50 Families Only data from one carer in each family included	FMSS GHQ ECI	<p><i>Decrease in EE</i> FMSS: C categorised as high EE (Cochran's $Q=5.8$; $df=2$; $p=0.01$). $T1(55\%)>T2(24\%)$ * $T2(24\%)<T3(35\%)$ * <i>Decreased in C distress</i> GHQ-12: ($F(2,29)=9.4$, $p=0.01$ $\eta^2=0.40$) $T1>T2^*$ and $T1>T3^*$ <i>Decrease in Negative aspects of caregiving</i> ECI-negative: $F(2,27)=5.3$, $p=0.01$ $\eta^2=0.30$)</p>
UK Moderate		Members of an ED team and two expert carers	N= 44 Parents N= 2 Sibling/other relative	N=35 AN N= 10 BN	Pre-treatment Post-treatment 3 month FU	T1 N=47 T2 N=46 T3 N=43 3 carers did not want to be included in the study		
Sepulveda et al. ⁴⁰	Before & after study	<u>Workshop Intervention :</u> 6 workshops over a 3 month period.	N=35 Carers	N=28 SU All Female Age ($M=22.7$, $SD=7.7$, range=15-33)	3 months	N= 33 Carers N= 28 Primary care givers Only data from primary caregiver used	GHQ ECI EDSIS	<p><i>Decreased in C distress</i> GHQ-12: ($F(2,14)=6.5$, $P=0.018$) $T1>T2$ * [$d=0.39$] $T1>T3^*$ [$d=0.5$] <i>Decrease in Negative aspects of caregiving</i> ECI –negative: ($F(2,17)=4.1$, $P=0.035$) $T1>T2^*$ [$d=0.68$] $T1>T3^*$ [$d=0.6$] EDSIS: ($F(2,17)=5.9$, $P=0.011$) $T1>T3^*$ [$d=0.59$]</p>
UK Moderate		Psychiatrist, social worker and nurse leader with extensive ED experience.	N=26 Parents N=1 Spouse N=1 Sibling	N= 22 AN N= 6 BN	Pre-treatment Post-treatment 3 month FU	T1 N=28 T2 N=22 T3 N=23		
Gísladóttir & Svavarsdóttir ³⁵	Before & after study	<u>Group Intervention:</u> 4 group sessions	N= 24 Carers	N=14 SU All female Age ($M=21$, range=15-31)	4 weeks	N=21 Carers	LEE ABOS FQ	<p><i>Increase in C Understanding of ED</i> LEE ($t(15)=2.78$, $p=0.014$, $d=.363$) <i>Improvements in ED symptoms- C report</i> ABOS subscale 'eating behaviours, concern with weight & food & denial of problem' ($t(18)=3.181$, $p=0.005$, $d=.487$)</p>
Iceland 15/31		Psychiatric nurse, Professor of Nursing and a PhD nursing student.	N=12 Mothers N= 7 Fathers N= 2 Siblings N=3 Partners	BN (57%) AN (19%) EDNOS (10%) Unknown (14%)	Pre-treatment Post-treatment	T1 N=24 T2 N=21 *Missing data –N analysed varied from 10 – 19*		

Table 3: Summary of studies included in systematic review of carers interventions in eating disorders (continued)

Uehara et al. ⁴²	Before & after study	<u>Workshop Intervention:</u> 5 workshops	N= 37 Carers	N=26 SU N=25 Female N=1 Male Age (<i>M</i> =20.1, <i>SD</i> =8.1, range=12-33)	5 months	N=28 Carers N= 26 Families Data from all completers included	FMSS FACES-KG POMS EDES GAF ABOS	<i>Improvement in SU functioning</i> - P reported GAF T1 >T2* (<i>t</i> (27)= 5.5, <i>d</i> =.44) <i>Improvement in ED symptoms</i> - C reported ABOS T1 <T2 (<i>t</i> (27)=3.0, <i>P</i> < .01, <i>d</i> =.32) <i>No improvement in ED symptoms</i> - P reported EDES (<i>P</i> >.05) <i>Improvements in aspects of</i> FF FACES-KG cohesion T1< T2 (<i>t</i> (27)=8.5, <i>P</i> <.01, <i>d</i> =1.161) FACES-KG adaptability T1 <T2* (<i>t</i> (27)=6.8, <i>d</i> =1.028) <i>Decrease in</i> EE FMSS: No. of high-EE relatives T1(29%) >T2(4%)* No. of relatives identified as no EOI T1(64.3%)<T2(92.9%)*
Japan		Information on professionals not provided	N=25 Mother N=1 Father N=1Grandmother N=1 Brother	N=18 AN N= 7 BN N=1 EDNOS	Pre-treatment Post-treatment	T1 N=37 T2 N=28		
Poor								
Sepulveda et al. ⁴¹	Before & after study	<u>DVD-based skills training</u> , supplemented with telephone coaching.	N= 16 Carers	N=14 SU N= 13 Female N= 1 Male Age (<i>M</i> =17.2, <i>SD</i> =4.3, range= 14-27)	3 months	N = 14 Carers	HADS GHQ ECI FQ	No significant findings but authors report that almost all the outcome measures showed an improvement T1 to T2 with effect sizes ranging from 0.10 to 0.53.
UK		Guidance was delivered by a nurse with expertise in ED & an expert carer.	N=13 female N=3 male (Relatives not further specified)	N= 11 AN N= 2 BN N = 1 Unknown	Pre-treatment Post-treatment	T1 = 16 T2 = 14		
Poor								
Outcome measures: Anorectic Behaviour Observation Scale Questionnaire (ABOS); Accommodation & Enabling Scale for Eating Disorders (AESED) ; The Revised Scale for Caregiving Self-Efficacy (CES); Eating Behaviours (EatBeh); The Experience of Care Giving Inventory (ECI) The Eating Disorders Symptoms Impact Scales (EDSIS); Eating Disorder Evaluation Scale (EDES); Family Adaptability & Cohesion Evaluation Scales - Japanese version (FACES-KG); Five Minute Speech Sample (FMSS); The Family Questionnaire (FQ); Global Assessment of Functioning Scale (GAF); Global Eating Disorders Functioning (GEDF); General Health Questionnaire (GHQ); Hospital Anxiety & Depression Scale (HADS); Level of Expressed Emotion (LEE); Profile of Mood States (POMS); Social Problem Solving Inventory – Revised (SPSI-R)								

DISCUSSION

This review explored the evidence base for educational and skills based carers interventions in the area of eating disorders. Eight studies were identified that reported on the clinical outcomes of interventions for carers of people with eating disorders. All studies have been published since 2001, with five publications within the past two years. This suggests increased awareness of carers' needs, and the importance of providing them with the support they require.

There were two main approaches to the delivery of interventions: self-help approaches^{36–38,41} and groups or workshops^{35,39,40,42}. There was a high degree of similarity in the core components of interventions across studies. Additionally, a number of key measures were used to assess carer outcomes in all good quality and most moderate quality studies. The most frequently assessed outcome domains were: carer distress, experience of caregiving and level of EE. The measures used to assess these domains are widely used, and well validated^{48,49,51,52,54–56}. The relative homogeneity of intervention components and outcome measures enhances our ability to compare findings across the reviewed studies, and draw conclusions based on these.

Main Findings

Six of the reviewed studies were rated as moderate to good quality^{36–40} and the remaining two were rated as poor quality^{41,42}. Significant positive findings were reported in seven studies^{36–40,42}. However, only the findings of studies of moderate to good quality will be considered in this discussion.

Carer distress was the most commonly assessed outcome. Significant reductions in carer distress were reported in five studies of moderate to good quality,

with effects sizes ranging from small to large where these were reported ^{36–40}. These studies comprised of three self-help interventions ^{36–38} and two workshop interventions ^{39,40}. The reduction in carer distress was maintained or further improved at follow-up in four studies ^{36,38–40}. Grover et al. ³⁷, failed to identify a significant effect at follow-up. However, it is noteworthy that Grover et al. ³⁷ experienced high rates of drop-out, with only 60.7% of the intervention group and 56.7% of the control group returning outcome measures at follow-up. Thus, the lack of a positive finding at follow up may reflect a Type II error due to the reduction in power.

Reductions in negative aspects of the caregiving experience and caregiving burden were reported across four studies of moderate to good quality ^{36,38–40}. Significant reduction in negative aspects of the caregiving experience were reported between baseline and post-intervention in both self-help ^{36,38} and workshop based interventions ^{39,40}. Effect sizes ranging from small to medium were reported in these studies. A significant increase on the positive aspects of the caregiving experience was also reported in one study ³⁸, although scores returned to baseline levels at follow-up and a small effect size was reported. Improvements in caregiving burden were reported between baseline and post-intervention or follow-up in three studies of moderate to good quality, with small to medium effect sizes ^{36,38,40}. These studies comprised of two self-help interventions ^{36,38} and one workshop intervention ⁴⁰.

Reductions in EE were reported in three studies of moderate to good quality ^{36,38,39}, including two self-help interventions ^{36,38} and one workshop intervention ³⁹. One study reported a further significant decrease between post-intervention and follow-up ³⁶, while another reported a significant reduction between baseline and follow-up, with a large effect size ³⁸. There were mixed findings regarding whether these changes reduced the proportion of carers categorised as high EE ^{38,39}. This

may relate to differences in the outcome measures used (self-report versus clinician-rated) or the nature of the interventions (self-help versus workshop).

Accommodation and enabling behaviours within the family were also assessed in two self-help studies of good quality ^{36,37}, with equivocal results. The failure to identify a significant positive effect in the study by Grover et al. ³⁷ may relate to the study being under powered, as a greater reduction in accommodation and enabling behaviours was identified in the intervention group.

Finally, service user outcomes were assessed in two studies of moderate to good quality ^{35,36}. This included one self-help study ³⁶ and one group intervention ³⁵. Both studies identified a significant reduction in carer reported eating disorder symptoms between baseline and post-intervention, with a further significant reduction at follow-up reported in one study ³⁶. It was only possible to determine an effect size for Gísladóttir & Svavarsdóttir ³⁵, which was small. While these findings may not reflect an objective change in eating disorder symptoms, it has been reported that caregiving burden and lowered quality of life amongst carers is related to their perception of severity of the eating disorder, which does not necessarily concur with objective assessment ^{13,16}. Thus, a reduction in perceived severity may benefit carers regardless of whether this reflects objective change.

Methodological limitation of reviewed studies

All the reviewed studies had methodological limitations. There are a number of key issues that increase the risk of bias and inaccurate findings within the included studies. Only two studies employed randomisation methods ^{36,37}. All other studies ^{35,38–42} employed 'before and after' designs, which are regarded as having a greater risk of bias by their use, as it can be more difficult to account for confounding variables ³¹. Attempts to conceal allocation or the timing of assessments from

assessors were reported in only three studies ^{36,37,39}. Furthermore, only one study contained a control group ³⁷. In the absence of a control group it is possible that findings within the remaining studies could have been influenced by other latent variables ^{35,36,38–42}.

Power calculations were not reported in most studies ^{35,38–42} and where these were reported, drop-out rates may have resulted in the studies being under powered ^{36,37}. Three studies failed to report adjusting for multiple comparisons in their results, leaving the findings vulnerable to Type I errors ^{35,41,42}. Furthermore, intention to treat analysis was not employed in any of the studies. Only three studies accounted for missing data in their analysis ^{36–38}, while the remaining studies used per protocol analysis ^{35,39–42}. Failure to account for all participants who started the intervention may exaggerate the treatment effect. Encouragingly, the two studies with the highest quality ratings were published within the past year ^{36,37}. This suggests that as the field is developing, the methodological standard of research is increasing.

Limitations of the Review

Due to practical issues related to accessing unpublished materials only studies from peer-reviewed publications were included in this review, this introduced a potential publication bias in the findings but also improved the quality of studies. Additionally, only publications in English were considered. This also has the potential to introduce bias as relevant studies from non-English speaking countries may have been excluded. The quality assessment checklist, Downs and Black ³², was adapted for the current review due to difficulties determining *a priori* sample size calculations for studies that employed Linear Mixed Methods Models ^{36–38}, hence there may not have been an adequate evaluation of power.

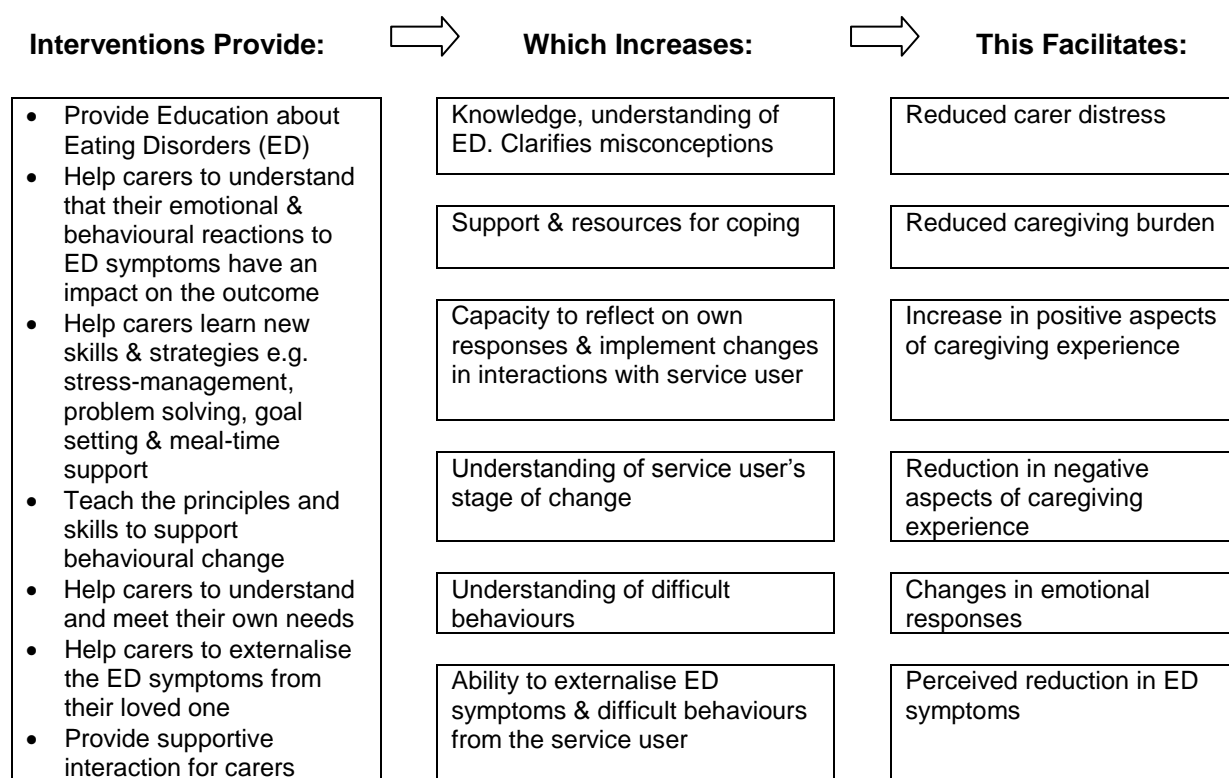
The majority of carers included in studies were mothers, thus the extent to which the findings can be generalised to fathers or other carers is limited. However, studies have identified that mothers experience higher levels of distress,¹⁵ and female caregivers generally report higher levels of burden than their male counterparts⁶⁴. Moreover, in AN it is high maternal criticism in particular, that has been found to impact outcomes and response to treatment^{23,27}, thus it may be appropriate to initially focus on this group of carers.

CONCLUSIONS

The findings from the reviewed studies provide tentative evidence for the clinical effectiveness of interventions for carers of individuals with eating disorders. There are initial indications that such interventions are beneficial for reducing carer distress and carer burden, improving negative aspects of the caregiving experience, and decreasing expressed emotion. There are also some indications that these approaches may help to improve the perceived severity of eating disorder symptoms.

There were no clear benefits of one intervention approach over the other. Both self-help and workshop interventions appeared to benefit carers. Indeed it appeared that it may be the components of interventions that were important, rather than the delivery format. Figure 2 (page 33) presents a diagrammatic representation of the key components of the interventions and hypothesised mechanisms by which they may impact carer outcomes.

Figure 2: Diagrammatic representation of synthesised findings



Implications for future research

The findings from the reviewed studies provide tentative evidence for the clinical effectiveness of interventions for carers of individuals with eating disorders, which would benefit from further methodologically sound studies. This could be achieved through the use of large RCT's, including treatment and control groups that are comparable at baseline.

As far as can be determined, the UK workshop intervention studies have all been undertaken by clinicians based at the Institute of Psychiatry, part of the South London and Maudsley NHS Foundation which is renowned for expertise in Eating Disorders. To increase the generalisability of research findings it would be helpful to undertake a multi-site study, involving a manualised workshop that can be delivered by clinicians in typical clinical settings. Clearer reporting of how therapist adherence to protocol is assessed would also be important in future research of this kind.

Further replication of findings from self-help studies is also warranted. Although larger scale studies have been undertaken, these have been hampered by higher rates of attrition. Every effort should be made to maintain retention rates in such studies and reasons for attrition should be ascertained so that factors contributing to this can be addressed.

Another important question to address would be whether self-help intervention works as effectively with, or without, supportive guidance. Initial evidence for comparability of self-help and guided self-help was provided by Goddard et al.³⁶. However, guidance was provided by both clinicians and non-clinicians (expert carers). It has been suggested that varied levels of expertise and training could perhaps reduce the effect of guidance³⁷, thus it would be important to compare the effectiveness of support delivered by clinicians versus non-clinicians.

A further avenue of research would be to compare the efficacy of interventions for different groups of carers, such as parents, partners or siblings. In undertaking further research in this area, researchers should aim to make use of the most commonly employed outcome measures, as outlined in this review, in order to increase consistency and comparability across studies.

Implications for Clinical Practice

The importance of addressing the needs of carers has been increasingly recognised by professionals in the field of eating disorders^{14–16}. The responsibility that services have to assess the needs of carers and provide them with support is also highlighted within recent Carers Strategies from both the British and Scottish Governments^{29,30}. The findings of this review indicate that educational and skills based interventions provide a promising means to provide such input, and should be considered as an adjunct to service provision in eating disorders.

References

1. Hudson J, Hiripi E, Pope Jr H, Kessler R. The prevalence and correlates of eating disorders in the National Comorbidity Survey Replication. *Biological Psychiatry*. 2007;61:348–58.
2. Wade T, Bergin J, Tiggemann M, Bulik C, Fairburn C. Prevalence and long-term course of lifetime eating disorders in an adult Australian twin cohort. *Australian and New Zealand Journal of Psychiatry*. 2006;40:121–8.
3. Carr A, McNulty M. *The handbook of adult clinical psychology: an evidence-based practice approach*. East Sussex, UK: Routledge; 2006.
4. Arcelus J, Bouman W, Morgan J. Treating young people with eating disorders: transition from child mental health to specialist adult eating disorder services. *European Eating Disorder Review*. 2008;16:30–6.
5. Royal College of Psychiatrists. *Eating disorders in the UK: policies for service development and training*. Report from the eating disorders special interest group. London: 2000.
6. Department of Health. *No Health Without Mental Health: A Cross-Government Mental Health Outcomes Strategy for People of All Ages* [Internet]. London: 2011. Available from: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_124006.pdf
7. The Scottish Government. *Mental Health Strategy for Scotland: 2011-15 A Consultation* [Internet]. Edinburgh: 2011. Available from: <http://www.scotland.gov.uk/Publications/2011/09/01163037/0>
8. National Institute for Clinical Excellence. *Eating disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders* [Internet]. London: 2004. Available from: <http://www.nice.org.uk/CG009NICEguideline>
9. Eisler I. The empirical and theoretical base for family therapy and multiple family day therapy for adolescent anorexia nervosa. *Journal of Family Therapy*. 2005;27:104–31.
10. le Grange D, Lock J, Loeb K, Nicholls D. Academy for Eating Disorders position paper: the role of the family in eating disorders. *International Journal of Eating Disorders*. 2010;43(1):1–5.
11. De la Rie SM, Van Furth EF, De Koning A, Noordenbos G, Donker MCH. The quality of life of family caregivers of eating disorder patients. *Eating Disorders*. 2005;13(4):345–51.
12. Treasure J, Whitaker W, Whitney J, Schmidt U. Working with families of adults with anorexia nervosa. *Journal of Family Therapy*. 2005 May;27(2):158–70.

13. Martin J, Padierna A, Aguirre U, Quintana J., Hayas CL, Munoz P. Quality of life among caregivers of patients with eating disorders. *Quality of Life Research*. 2011;20:1359–69.
14. Graap H, Bleich S, Herbst F, Trostmann Y, Wancata J, De Zwaan M. The needs of carers of patients with anorexia and bulimia nervosa. *European Eating Disorders Review*. 2008;16:21–9.
15. Kyriacou O, Treasure J, Schmidt U. Understanding how parents cope with living with someone with anorexia nervosa: modelling the factors that are associated with carer distress. *International Journal of Eating Disorders*. 2008;41:233–42.
16. Zabala MJ, Macdonald P, Treasure J. Appraisal of caregiving burden, expressed emotion and psychological distress in families of people with eating disorders: a systematic review. *European Eating Disorder Review*. 2009;17(5):338–49.
17. Haigh R, Treasure J. Investigating the needs of carers in the area of eating disorders: development of the Carers' Needs Assessment Measure (CaNAM). *European Eating Disorders Review*. 2003;11:125–41.
18. Winn S, Perkins S, Murray J, Murphy R, Schmidt U. A qualitative study of the experience of caring for a person with bulimia nervosa. Part 2: carers' needs and experiences of services and other supports. *International Journal of Eating Disorders*. 2004;36:269–79.
19. Highet N, Thompson M, King RM. The experience of living with a person with a eating disorder: the impact on the carers. *Eating disorders*. 2005;13:327–44.
20. Hillege S, Beale B, McMaster R. Impact of eating disorders on family life: individual parents' stories. *Journal of Clinical Nursing*. 2006;15:1016–22.
21. Tierney S. The treatment of adolescent anorexia nervosa: a qualitative study of the views of parents. *Eating Disorders*. 2005;13:369–79.
22. Perkins S, Winn S, Murray J, Murphy R, Schmidt U. A qualitative study of the experience of caring for a person with bulimia nervosa. Part 1: the emotional impact of caring. *International Journal of Eating Disorders*. 2004;36:256–68.
23. van Furth EF, van Strien DC, Martina LM, van Son MJ, Hendrickx JJ, van Engeland H. Expressed emotion and the prediction of outcome in adolescent eating disorders. *International Journal of Eating Disorders*. 1996 Jul;20(1):19–31.
24. Nilsson K, Engström I, Hägglöf B. Family climate and recovery in adolescent onset eating disorders: a prospective study. *European Eating Disorder Review* 2012;20(1):e96–102.

25. Whitney J, Murray J, Gavan K, Todd G, Whitaker W, Treasure J. Experience of caring for someone with anorexia nervosa: qualitative study. *The British Journal of Psychiatry*. 2005;187:444–9.
26. Hooley J. Expressed Emotion and Relapse of Psychopathology. *Annual Review of Clinical Psychology*. 2007;3:329–52.
27. Eisler I, Dare C, Hodes M, Russell G, Dodge E, Le Grange D. Family therapy for adolescent anorexia nervosa: the results of a controlled comparison of two family interventions. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*. 2000;41(6):727–36.
28. Schmidt U, Treasure J. Anorexia nervosa: Valued and visible. A cognitive-interpersonal maintenance model and its implications for research and practice. *British Journal of Clinical Psychology*. 2006;45(3):343–66.
29. The Scottish Government. Caring Together: The Carers Strategy for Scotland 2010-2015 [Internet]. Edinburgh: 2010. Available from: <http://www.scotland.gov.uk/Resource/Doc/319441/0102104.pdf>
30. Department of Health. Recognised, Valued and Supported: Next steps for the Carers Strategy [Internet]. 2010. Available from: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_122393.pdf
31. CRD, editor. Systematic Reviews: CRD's guidance for undertaking reviews in healthcare [Internet]. York: Centre for Research and Dissemination, University of York; 2008. Available from: http://www.york.ac.uk/inst/crd/pdf/Systematic_Reviews.pdf
32. Downs SH, Black N. The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology and Community Health*. 1998;52(6):377–84.
33. Deeks JJ, Dinnes J, D'Amico R, Sowden a J, Sakarovich C, Song F, et al. Evaluating non-randomised intervention studies. *Health technology assessment (Winchester, England)* [Internet]. 2003 Jan;7(27):iii-x, 1–173. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/14499048>
34. Egger M, Davey Smith G. Misleading meta-analysis. *British Medical Journal*. 1995;310:752–4.
35. Gísladóttir M, Svavarsdóttir EK. Educational and support intervention to help families assist in the recovery of relatives with eating disorders. *Journal of Psychiatric and Mental Health Nursing*. 2011;18(2):122–30.
36. Goddard E, Macdonald P, Sepulveda a. R, Naumann U, Landau S, Schmidt U, et al. Cognitive interpersonal maintenance model of eating disorders: intervention for carers. *The British Journal of Psychiatry*. 2011;199(3):225–31.

37. Grover M, Naumann U, Mohammad-Dar L, Glennon D, Ringwood S, Eisler I, et al. A randomized controlled trial of an Internet-based cognitive-behavioural skills package for carers of people with anorexia nervosa. *Psychological Medicine*. 2011; 41:2581-2591
38. Grover M, Williams C, Eisler I, Fairbairn P, McCloskey C, Smith G, et al. An off-line pilot evaluation of a web-based systemic cognitive-behavioral intervention for carers of people with anorexia nervosa. *International Journal of Eating Disorders*. 2011;44(8):708–15.
39. Sepulveda AR, Todd G, Whitaker W, Grover M, Stahl D, Treasure J. Expressed emotion in relatives of patients with eating disorders following skills training program. *International Journal of Eating Disorders*. 2010;43(7):603–10.
40. Sepulveda AR, Lopez C, Todd G, Whitaker W, Treasure J. An examination of the impact of “the Maudsley eating disorder collaborative care skills workshops” on the well being of carers: a pilot study. *Social Psychiatry and Psychiatric Epidemiology*. 2008;43(7):584–91.
41. Sepulveda AR, Lopez C, Macdonald P, Treasure J. Feasibility and acceptability of DVD and telephone coaching-based skills training for carers of people with an eating disorder. *International Journal of Eating Disorders*. 2008;41(4):318–25.
42. Uehara T, Kawashima Y, Goto M, Tasaki SI, Someya T. Psychoeducation for the families of patients with eating disorders and changes in expressed emotion: A preliminary study. *Comprehensive psychiatry*. 2001;42(2):132–8.
43. Crown. Education and Training Statistics for the United Kingdom 2011 [Internet]. UK: 2011. Available from: <http://www.education.gov.uk/rsgateway/DB/VOL/v001045/index.shtml>
44. Eurostat. Education statistics at regional level [Internet]. European Commission. 2012 [cited 2012 Jun 19];Available from: http://epp.eurostat.ec.europa.eu/statistics_explained/
45. Crown. Labour Market Statistics 2008-2012 [Internet]. Office of National Statistics. Available from: http://www.ons.gov.uk/ons/publications/all-releases.html?newquery=*&newoffset=25&pageSize=25&definition=77-21589
46. Treasure J, Sepulveda A, Whitaker W, Todd G, Lopez C, Whitney J. Collaborative care between professionals and non-professionals in the management of eating disorders: a description of workshops focussed on interpersonal maintaining factors. *European Eating Disorder Review*. 2007;15(1):24–34.
47. Williams C. *Overcoming Depression: A Five Areas Approach*. London: Arnold; 2001.

48. Zigmond A, Snaith R. The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*. 1983;67:361–70.
49. Goldberg D, Williams P. Users' guide to the General Health Questionnaire. UK: NFER-Nelson; 1988.
50. Yokoyama K, Araki S. POMS Japanese version II. Tokyo: Kaneko Shobo; 1991.
51. Szmukler G, Burgess P, Herrmann H, Benson A, Colusa S, Bloch S. Caring for relatives with serious mental illness: the development of the Experience of Caregiving Inventory. *Social Psychiatry and Psychiatric Epidemiology*. 1996;31(137-48).
52. Sepulveda A, Whitney J, Hankins M, Treasure J. Development and validation of an Eating Disorders Symptom Impact Scale (EDSIS) for carers of people with eating disorders. *Health and Quality of Life Outcomes*. 2008;6:28–36.
53. Steffen A, McKibbin C, Zeiss A, Gallagher-Thompson, Bandura A. The revised scale for caregiving self-efficacy: reliability and validity studies. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*. 2002;57B:74–86.
54. Magana A, Goldstein M, Karno M, Miklowitz D, Jenkins J, Falloon I. A brief method for assessing expressed emotion in relatives of psychiatric patients. *Psychiatry Research*. 1986;17:203–12.
55. Cole J, Kazarian S. Predictive validity of the Level of Expressed Emotion (LEE) Scale: readmission follow-up data for 1, 2, and 5-year periods. *Journal of Clinical Psychology*. 1993;49:216–8.
56. Wiedemann G, Rayki O, Feinstein E, Hahlweg K. The Family Questionnaire: development and validation of a new self-report scale for assessing expressed emotion. *Psychiatry Research*. 2002;109:265–79.
57. Olson D, Porer J, Lavee Y. FACES III. Minnesota: St. Paul, University of Minnesota; 1985.
58. Sepulveda A, Kyriacou O, Treasure J. Development and validation of the Accommodation and Enabling Scale for Eating Disorders (AESED) for caregivers in eating disorders. *BMC Health Services Research*. 2009;9:171–83.
59. Vanderlinden J, Norre J, Vandereycken W. Appendix A—EDES. In: *A Practical Guide to the Treatment of Bulimia Nervosa*. Tokyo: Seiwa Shoten; 1995. p. 223–5.
60. Endicott J, Spitzer R, Fleiss J, Cohen J. The global assessment scale. A procedure for measuring overall severity of psychiatric disturbance. *Archives of General Psychiatry*. 1976;33(766-71).

61. Vandereycken W. Validity and reliability of the anorectic behavior observation scale for parents. *Acta Psychiatrica Scandinavica*. 1992;85:163–6.
62. D’Zurilla T, Nezu A, Maydeu-Olivares A. (SPSI-R). Manual for the Social Problem-Solving Inventory-Revised. Tonawanda, NY: Multi-Health Systems Inc.; 1996.
63. Gueorguieva R, Krystal J. Move Over ANOVA Progress in Analyzing Repeated-Measures Data and Its Reflection in Papers Published in the Archives of General Psychiatry. *Archives of General Psychiatry*. 2004;61(3):310–7.
64. Dimitropoulos G, Carter J, Schachter R, Woodside D. Predictors of family functioning in carers of individuals with anorexia nervosa. *International Journal of Eating Disorders*. 2008;41(8):739–47.

Chapter Two: Major Research Project

The transition from child and adolescent to adult services in eating disorders: A qualitative study of service user and carer perspectives

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Abstract

Objective: The transition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS) can be a challenging time for young people with eating disorders and their families. The current study explored the transition between CAMHS and AMHS from the perspectives of service users and carers.

Method: Participants were recruited from NHS Services in the West of Scotland region. A sample of six service users and five carers participated in the study. Interpretative phenomenological analysis was used to explore participants' experiences of transition.

Results: Three superordinate themes emerged from the data: 'Transition Experience', 'Shift in Treatment Ethos' and 'Outcome of Transition'. There was a high degree of agreement between the accounts of services users and carers.

Discussion: The prospect of transition was associated with feelings anxiety for most participants. Transitions that were planned and co-ordinated provided the best continuity of care, while an absence of transition planning was associated with disruptions of care and negative outcomes. The importance of determining decisions about transition on an individual basis was highlighted. Differences in treatment approach between CAMHS and AMHS were explored. Service users experienced increased autonomy in AMHS, while carers were more often excluded from treatment. There was divergence in how participants viewed these changes. These findings offer insights into how services may support the transition from CAMHS to AMHS, elaborating upon and adding to, clinical guidelines for transitional care.

Lay Summary

The move from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS) in eating disorders can be a challenging time for young people and their families. Clinical features of eating disorders, such as fear of maturity, low self-esteem, high mortality rates and the increased risk associated with times of transition, present unique issues for transitional care in this area. To date, there has been limited research regarding transitional care in eating disorders. This study aimed to explore the transition between CAMHS and AMHS from the perspectives of young people with eating disorders and carers who had been through this process.

Six service users and five carers were interviewed about their experiences. The prospect of moving from CAMHS to AMHS was associated with feelings anxiety for most participants. Transitions that were planned and co-ordinated helped to provide a seamless move between services. Where there was an absence of transition planning this was associated with disruptions of care. The importance of decisions about transition being determined on an individual basis was highlighted. Differences in treatment approach between CAMHS and AMHS were explored. Service users experienced increased independence in AMHS, while carers were often excluded from treatment. There were differences in how participants viewed these changes. These findings offer insights into how services may support the process of transition.

INTRODUCTION

Eating disorders are a group of serious mental health conditions that include anorexia nervosa (AN), bulimia nervosa (BN) and eating disorders not otherwise specified. These conditions are characterised by over-evaluation of weight and shape, and the ability to control these, whereby the individual will mainly judge their self-worth in terms of these ¹⁻³.

A range of genetic, biological, psychological and social factors are associated with the development and maintenance of eating disorders ⁴. Individual factors implicated in eating disorders include low self-esteem, perfectionism and difficulties regulating mood states ^{1,5,6}. Interpersonal factors include family tension, family history of eating disorders/dieting, and high expressed emotion in close others. High expressed emotion may occur as a result of the impact of the eating disorder within the family and unintentionally serve to reinforce eating disorder behaviours ⁴⁻⁶. As a result of dietary restraint there can be physiological and cognitive changes that serve to maintain the condition ^{5,6}.

For the individual with an eating disorder, their condition may serve a valued function, such as providing a sense of control, a sense of achievement, a way of avoiding difficult emotions or communicating these to others, or a means of avoiding difficulties related to the transition to adulthood ^{5,7}. Given the potential functions an eating disorder may serve, it is unsurprising that ambivalence about recovery is common amongst individuals with these conditions. Indeed for some individuals, the thought of giving up their eating disorder may be a frightening prospect ^{5,8}.

Eating disorders most commonly affect young women, with the peak age of onset during mid to late adolescence. The estimated prevalence of eating disorders amongst this population is 1-1.5% ^{9,10}. Eating disorders are associated with

significant co-morbid physical, psychological, social and occupational problems. Moreover, AN is associated with a high mortality rate ¹¹. Approximately one fifth of individuals with AN and BN will develop a chronic course of illness ^{12,13} and up to half of individuals will only experience a partial recovery ¹². Owing to age of onset and course of eating disorders, a proportion of young people and their families will experience a transition of care from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS). Within this report the acronym AMHS will be used to refer to all adult mental health services including specialist and non-specialist services.

There is widespread recognition that the transition from child to adult healthcare services can be problematic, with poorly defined procedures and a lack of co-ordinated care planning ^{14–17}. This area has gained attention in recent decades as medical advances have led to an increased life expectancy for young people with chronic illnesses, physical disabilities and learning disabilities ¹⁸. In the latest government review of services to children and adolescents, the problem of transition was identified as a critical area for policy ¹⁵. Kennedy ¹⁵ (p.37) reported that young people may experience transition as “a disruptive discontinuity to their care”. Moreover, many young people fall through gaps between services, failing to meet thresholds for adult services or being lost during the transition. A disruption of care during transition can negatively impact on compliance with treatment, physical health, mental well-being and engagement with services ^{14,18}.

These transitions occur at a time when young people and their families may be experiencing significant change in other aspects of life. Adolescence is a time of increased autonomy and individuation from family of origin. The shift in treatment ethos from child to adult services mirrors this. The systemic approach of child

services, which involves parents in treatment and decision making processes, is replaced by a more individualistic model. Young people are expected to become more autonomous and assume responsibility for their healthcare ¹⁷. Research suggests that young people value having increased control of their healthcare and the opportunity to be seen independently. For parents, issues of confidentiality and consent can significantly alter their involvement in treatment. Parents have to adapt to their changing role; for some this may be experienced as a loss or they may fear relinquishing control ^{14,18}.

Recent policy documents and guidelines have started to address transitional issues. A number of key recommendations have emerged including: early identification of those likely to require transitional care, assessing readiness for transition, sensitivity to developmental needs, working with young people to prepare for transition, promotion of self-reliance while working closely with carers and joint working between services. The overarching message emerging from these documents is that the transition from child to adult services should be viewed as a flexible process rather than a single event, the timing and length of which should be individually determined ^{14–17,19,20}.

Additional considerations may be required when addressing transitional issues in eating disorders. Times of transition are considered to pose an increased risk in some eating disorders ²¹. Treasure, Schmidt & Hugo ²² suggest that the sudden change in treatment ethos, can be confusing and dangerous for young people with eating disorders and their families. Young people with the greatest severity of illness may experience difficulties with an “adult-like approach” due to fears of maturity and low self-esteem. At the same time, their parents may find that they become excluded from decisions about care ²³.

The transition from CAMHS to AMHS has been identified as a time of particular difficulty for parents of individuals with eating disorders, due to the loss of parental influence on treatment and a lack of feedback from professionals ²⁴. Carers have highlighted the need for more information and support from AMHS to help in dealing with the eating disorder ^{24–28}.

Clinical recommendations for the management of transitions between CAMHS and AMHS in eating disorders have been identified within two reports ^{23,29}. Recommendations include the assessment of an individual's level of maturity and decision-making ability, adoption of a needs lead approach, the gradual introduction of an “adult like approach” and close collaboration between CAMHS and AMHS. The continuity of family involvement is also advised. Indeed, given the high mortality rate associated with eating disorders, Treasure et al. ³⁰ advise that in cases with serious medical risks, information sharing between professionals and carers is vital.

Over the past decade, service user and carer perspectives have gained increasing credence within the United Kingdom. Government strategies place patients at the heart of the NHS and emphasise the importance of involving service users and carers in the planning, designing and delivery of services to achieve this vision ^{31,32}. It is recognised that in order to meet the needs of children, young people, families and carers, we must listen to their experiences and gather information on their priorities so that services can be responsive to these ¹⁶.

The transition from CAMHS to AMHS may be experienced as a challenging time for young people with eating disorders and their families. Clinical features of eating disorders, such as fear of maturity and low self-esteem, high mortality rates and the increased risk associated with times of transition, present unique issues for transitional care in this area. To date, there has been limited research regarding

transitional care in eating disorders. No studies have been identified that explore the experience of transition from a service user or carer perspective. As such, it remains unclear what priorities they have for transitional care and how their needs can be best met by services. This has been recommended as a key area for audit within the most recent Report from the Royal College of Psychiatrists Section of Eating Disorders³³.

The aim of the current study is to explore service user and carer experiences of the transition between CAMHS and AMHS in eating disorders, using a qualitative approach. The use of a qualitative research methodology was felt to be particularly suited to exploring experiences of transitional care, as qualitative methods aim to develop a detailed understanding of participants' perspectives³⁴.

METHOD

Design

This study employed an interpretative phenomenological analysis (IPA) approach. IPA is a qualitative research methodology that has its theoretical groundings in the idiographic, phenomenological, and hermeneutic traditions^{35,36}. This approach was favoured over other qualitative methodologies, as it aims to gain a detailed understanding of participants' views and experiences of the phenomena of interest. IPA is concerned with understanding the 'lived experience' of individuals who share a particular experience, how each individual makes sense of their experience, and the meanings they attach to it^{35,37}. This is in contrast to other qualitative approaches such as Grounded Theory, which endeavours to identify, and provide a detailed account of contextualised social processes, with the aim of generating a theory about the phenomena of interest³⁷.

Researchers in IPA have a dynamic and interpretative role. It is recognised that the researcher's own beliefs, and assumptions will influence how they make sense of the participant's account. This creates a dynamic two-stage interpretative element to the process. It is advised that researchers reflect on their own conceptions and try to suspend these during the research process so that they do not overtly influence the process^{36,38}.

IPA literature recommends obtaining a purposive sample of participants. This refers to a predefined group of individuals who through personal experiences may provide insight into the phenomena under study^{35,38}. Researchers generally aim to obtain a fairly homogenous sample of participants. However, Smith et al.³⁵ (p.49) suggest that it may be useful to split the sample so that the phenomenon can be understood from different perspectives. The current study adopted this approach, as it was felt to be important to obtain both service user and carer perspectives on the transition to adult services.

Recruitment

Prior to commencing recruitment, ethical approval for the study was obtained from the West of Scotland Research Ethics Committee (reference: 11/WS/0050; Appendix 2.1). As it was envisaged that the potential pool of participants would be small, Research and Development Management Approval was obtained for all healthboards within the West of Scotland region: NHS Lanarkshire; NHS Greater Glasgow & Clyde; NHS Dumfries & Galloway; NHS Ayrshire & Arran (Appendices 2.2 - 2.6).

Recruitment took place between January 2012 and May 2012. Participants were primarily recruited via Specialist Eating Disorder Services across the four health board regions. Within NHS Lanarkshire, participants were also recruited

through Community Mental Health Teams. AMHS clinicians were informed of the eligibility criteria and were asked to identify potential participants from their caseloads. The eligibility criteria for service users and carers are detailed below in Table 1.

In addition to the above recruitment strategy, an advertisement was placed in the Scottish Eating Disorder Interest Group (SEDIG) newsletter (see Appendix 2.11) and the chief investigator (SOL) attended a carers group in Lanarkshire to promote the study to potential participants. Unfortunately, it was not possible to attend carers groups in other regions, as groups were not running during the recruitment period or this was not permitted by the regulations of the organisation overseeing the group.

Table 1: *Eligibility criteria*

Service User	Carer
<ul style="list-style-type: none"> - Aged 16 or over with a diagnosis of Anorexia Nervosa, Bulimia Nervosa or eating disorder not otherwise specified. - Have experienced a transition of care from child and adolescent mental health services to adult mental health services in the past 5 years whilst being treated for an eating disorder. - Currently receiving treatment for an eating disorder or have undergone a planned discharge from adult services. - Able to provide informed consent. - Deemed fit to participate by clinicians involved in their care 	<ul style="list-style-type: none"> - Individuals who are identified as a caregiver for an individual who meets the service user eligibility criteria. - Able to provide informed consent

A total of 10 service users were identified who met eligibility criteria, and were considered suitable to participate by clinicians involved in their care. All potential service users participants and their carers were provided with an information pack about the study via their clinical team. Two carers were also provided with information packs through the carers group, although both had already been identified by their local team. Information packs contained an information sheet and an opt-in form (Appendix 2.7 & 2.8). Service users and carers who were interested in participating were invited to contact the researcher by completing and returning the opt-in form. Those who 'opted-in' were contacted by the chief investigator (SOL). Further information about the study was provided and if, following this, potential participants agreed to take part in the study, arrangements were made for interviews.

A total of fourteen potential participants opted in to the study; eight service users and six carers. One service user withdrew from the study as she experienced deterioration in her illness and another service user ceased contact with the research team. One carer failed to attend for interview on two occasions, the reasons for which are unknown. However, her daughter was the above mentioned individual who experienced deterioration in her illness.

Participants

Eleven individuals participated in the current study. This sample comprised of six service users and five carers. The sample size was determined in accordance with guidance from leading researchers in IPA, which suggests that a sample of between four and ten participants is typically sufficient for researchers adopting this approach in a professional doctorate ³⁵.

All service users were females, aged between eighteen and twenty-one at the time of interview. Table 2 (page 52) provides a summary of the clinical

characteristics of service users. Gender appropriate pseudonyms have been provided to preserve the anonymity of participants.

Table 2: *Clinical characteristics of service users*

	Service Users					
	Amy	Becky	Claire	Donna	Elaine	Fiona
Diagnosis	AN	AN	AN	AN	AN	BN
Age at Onset of ED	13	10	13	17	14yr 11mth	14
Severity of ED	Severe	Severe	V. Severe	Moderate	Moderate	Severe
Age at Transition	17yr 11mth	17y	16 y	17yr 6mth	17yr 4mth	18y
Duration of transition	3mth	9mth	1mth	2mhs	4mth	6mth
Duration of ED	5 yr plus	7 yr	9 y	2yr 1mth	5yr 9mth	6y
Current Severity ED	Low Severity	Moderate	V. Severe	Low Risk	Moderate	In recovery
Eating disorder (ED); Anorexia Nervosa (AN); Bulimia Nervosa (BN); Years (yr); Months (mth)						

One male and four female carers participated in the study. All carers were parents in their mid-forties to mid-fifties. Four of the carers were parents of service users who also participated in the study. In order to minimise the chance of participant characteristics being recognisable, these dyads will not be identified. Carer characteristics can be found in Table 3.

Table 3: *Characteristics of carers*

	Carers				
	Audrey	Barbara	Cathy	David	Erica
Age Bracket	Mid-forties	Late forties	Mid-forties	Early fifties	Late forties
Employment status	Unemployed	Employed	Employed	Retired	Employed
Number of children	2	2	2	1	2

Data Collection

Data was collected through semi-structured interviews. Interviews were conducted on an individual basis by the chief investigator. All interviews were conducted in a private room on NHS premises within normal working hours. Prior to commencing interviews, written consent was sought from all participants. This included consent to participation, the recording of interviews and publication of anonymised quotations (see Appendix 2.9). Consent was also requested from service users to obtain basic clinical information from their key worker or former key worker (see Appendix 2.10).

Semi-structured interview schedules for carers and service users were developed, based on key issues identified from the aforementioned literature on transitional care (see Appendix 2.12). Interviews were conducted in a flexible manner, using open ended questions with further probes and specific questions as required, to encourage participants to elaborate on important topics. Participants were encouraged to talk as broadly as possible about their experiences of the transition between CAMHS and AMHS, and their views on this. Participants were also encouraged to discuss their experiences of child and adult services, and the differences between these, to provide contextual information for understanding their transition. Throughout the interview, an emphasis was placed on establishing rapport and trying to understand the participant's perspective. Empathetic communication skills such as active listening, acknowledgement, validation, and summarising were used to facilitate this process.

The length of interviews was consistently greater for carers than service users. Carers interviews ranged between 52 minutes and 106 minutes (average 78 minutes), while service user interviews ranged from 27 minutes to 57 minutes

(average 37 minutes). All interviews were transcribed verbatim by the chief investigator. In addition to assigning pseudonyms to participants, any identifying information such as references to places and other people were removed or anonymised. In instances where service users are referred to by name in quotes from their parents, pseudonyms have been used. Where these are individuals listed in table 2, alternative pseudonyms have been provided.

Data analysis

Analysis of the data was conducted in accordance with the recognised process in IPA^{35,38}. In keeping with the idiographic approach, each transcript was thoroughly analysed on an individual basis before progressing to analysis of the next transcript.

The first stage of this process involved several readings of the interview transcript, to become as familiar as possible with the account. Stage two began with noting points of interest in the transcript. Some notes were descriptive comments attempting to summarise or paraphrase the participant's account. Others explored the use of language in the transcript, making note of metaphors and connections to concepts or literature. The third stage involved the development of emergent themes. Through an iterative process, core issues were identified and clustered together into themes, which were then given a title. In the fourth stage, connections across the emergent themes were sought to develop higher order themes. This process was carried out with each interview transcript and patterns across cases were then explored. Finally, list of superordinate themes was developed. An example of the coding process is provided in Appendix 2.13. Given the large sample in the current study, for a theme to be included as a superordinate theme, evidence of reoccurrence across cases was necessary. This was defined as the presence of a theme in all participants' accounts^{35,38}.

All transcripts were analysed by the chief investigator. To assess the reliability and validity of coding procedure, the first two transcripts were also analysed in detail by an experienced qualitative researcher. Discussion of emergent themes identified a high level of agreement.

Reflexivity

Personal reflexivity refers to the process of reflecting upon how one's own beliefs, attitudes and experiences may influence the way in which we understand and interpret another person's experiences ³⁹. This is an important feature of IPA. The chief investigator had no experience working with individuals with eating disorders or their carers prior to undertaking this study. However, she attended a carers conference arranged by SEDIG the year before commencing recruitment. As a result of this, she had some insight into the challenges carers faced in relation to accessing information and support, and was aware of her admiration for the commitment these individuals show in supporting their loved ones. Additionally, as a female in her late twenties undertaking a Doctorate at the time of the research, the chief investigator could identify with aspects of service users accounts, such as striving in relation to academic achievements. The chief investigator was able to reflect on these issues prior to and during the research process, helping to maintain a balanced and open-minded approach.

RESULTS

Setting the scene

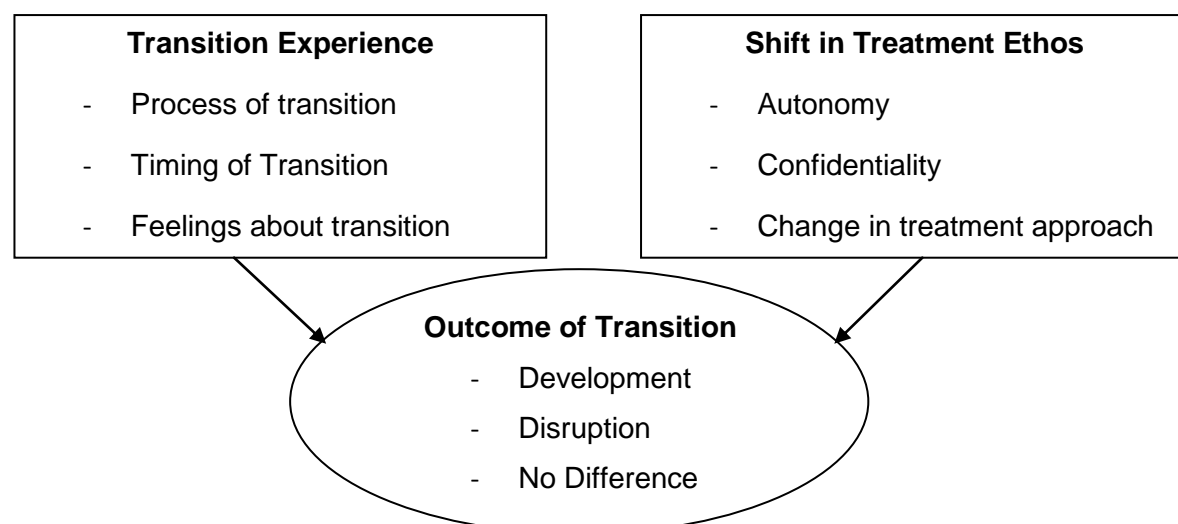
The aim of this study was to develop an understanding of how the transition between CAMHS and AMHS is experienced by young people with eating disorders and their carers. However, during the interview process it quickly became apparent

that young people with eating disorders experience multiple points of transition during their journey of care. These include transitions between Tier Two (Community Mental Health), Tier Three (Specialist Eating Disorder) and Tier Four (Inpatient) services, as well as CAMHS and AMHS. All but one participant reported five to seven transition points. Thus, while the focus will remain on transition between CAMHS and AMHS, salient information about the process of transition across the journey of care will be incorporated within the themes. The complexity of transitional care in eating disorders is illustrated in the following quote from nineteen-year-old Donna:

“I don’t know. I’ve just been in so many meetings in my life it’s quite hard to remember... I think the problem is that I’ve gone from child services, a little bit of adult, then to [Specialist Eating Disorders Service] and then back into ordinary adult... I’ve jumped around a lot” (Donna, P7:L14)

Three superordinate themes related to the transition from CAMHS to AMHS emerged from participants’ accounts. These were: ‘Transition Experience’, ‘Shift in Treatment Ethos’ and ‘Outcome of Transition’. A model of the emergent themes is illustrated in Figure 1.

Figure 1: Model of emergent themes



Theme 1: Transition Experience

All participants discussed their personal experience of the transition from CAMHS to AMHS. There were three themes which formed this superordinate theme: *process of transition, timing of transition and feelings about transition.*

Process of transition

There was considerable variation in participants' experiences of moving from CAMHS and AMHS. However, the presence or absence of plans and preparation to support the process of transition was remarked on by all. The majority of service users reported being involved in preparations for the transition. This ranged from attending a one off meeting with professionals from both services, to visiting the new team and having a period of crossover in service provision. Where service users' described a greater level of preparation for transition they spoke positively about this experience. Eighteen-year-old Amy, who had recently transitioned to AMHS, described good continuity of care during her transition with parallel care between CAMHS and AMHS:

"It was quite good that there was an overlap and I was still seeing people that I knew at the same time as being seen by someone that I didn't know. " (Amy, P12:L3)

Twenty-one-year-old Fiona recalled having the opportunity to meet members of the new team, which helped to ease her anxieties about the transition from hospital to community services:

"I think I met them all separately and they told me what their role would be in my treatment... it was helpful to meet them before I came out of hospital, cause it made me feel a bit more at ease." (Fiona, P5:L12)

Only two carers reported involvement in transition planning. Carers' appraisals were more neutral and it appeared that it was difficult for them to separate their experience of the transition process from other concerns about the move to adult services. David, a retired father of one, described involvement in transition meetings:

"As far as setting up meetings for the transition was concerned, I appreciated that was done fairly well" (David, P25:L8)

When carers and service users reported that they were not involved in planning or preparation for transition there was a desire for more information, involvement in decisions and better continuity of care. Eighteen-year-old Becky indicated that she would have liked to have been kept informed about the process:

"I just think that like the child services should have spoke to me more about it, like they didn't really tell me what was going on" (Becky, P6:L33)

Cathy, a mother of two in her mid-forties, used her experience of a later transition within adult services to suggest how the move from CAMHS and AMHS could have been improved for her daughter:

"If we could have had even a couple of sessions of meeting the new team and they could have got to know Tina and then picked up exactly when the other one finished..." (Cathy, P10:L17)

Several participants who reported an absence of transition planning described a disruption of care between CAMHS and AMHS. Disruptions of care included gaps in service provision and discrepancies between perceived level of service user needs and the level of input provided. Twenty-one-year-old Claire provided a stark description of discontinuity during her transition from CAMHS to AMHS:

“He [child clinician] got in touch with... it wasn’t here it was the adult services... he kind of referred me to there and stopped seeing me but it was about nine months before we heard anything from the adult services.” (Claire, P6:38)

Barbara, a mother of two in her late-forties, outlined her concerns about the level of input her daughter received following transition to adult services. Her use of language conveys a sense of her daughter floating in a gap between services:

“There was a few months, as I say where Aislinn seemed to be floating about and we were going ‘what’s happening, when are you going to see somebody?’ and I felt she wasn’t getting enough input.” (Barbara, P11:L22)

Service users and carers clearly valued the opportunity to be involved in planning and preparation for the transition from CAMHS to AMHS. While being kept informed and involved in meetings was considered helpful, it would appear the more detailed transition plans, including meeting new clinicians, joint working between teams and a period of parallel care, provided participants with the best continuity of care.

Timing of transition

All participants reported that the timing of their transition from CAMHS to AMHS was based on chronological age, although the transition age varied from sixteen to eighteen between regions. In regions where the age of transition was sixteen, participants indicated that there was some flexibility to remain at CAMHS while service users were attending secondary education. However, those who remained at CAMHS appraised this negatively, for reasons that will be discussed below and in subsequent sections.

The timing of transition was an important issue for service users, but appeared less so for carers. However, where carers remarked upon this issue, there was generally agreement with views expressed by service users. The predominant view expressed by service users was that the approach to treatment in CAMHS was not suited to their developmental stage as they reached late adolescence. This is illustrated by the following quote from Becky:

"I think they just like treated you like a child, like even, like I know seventeen isn't that old but they did kind of treat you like you were a child... like the whole environment of it and just the way they spoke to you it was just like you were a child" (Becky, P5:L8)

Amy's experience, however, differs markedly. She indicated that due to her illness she has missed out on normative adolescent developmental milestones, and thus had not achieved the level of maturity that may typically be expected at the age of eighteen. As a result she has struggled with her recent move to adult services:

"I must have been just about to go onto eighteen but I wasn't... I'd missed the whole fifth year at school so I'd missed out on all of that chance to grow up or whatever." (Amy, P14:L30)

There was agreement between Amy and her parent on this issue within the interviews. Both remarked on how this impacted on the transition to adult services, which will be discussed further in theme two.

Two participants reflected on their personal experiences to make suggestions regarding how the timing of transitions may be improved. Donna, who was referred to CAMHS at the age of seventeen and a half, spoke of the need for decisions to be individually determined so as to take account of developmental needs:

“I think it should maybe be more assessed on the individual patient rather just ‘oh you’re not 18 so you’re in CAMHS.’ I think that’s maybe something that needs to change... cause some people are more mature and some people are less mature.”

(Donna, P5:L22)

David, echoed this view. His use of language conveys a sense of frustration with the perceived rigidity of service structures, in which the timing of transition is primarily determined by chronological age:

“It should be... what’s... what’s best for this patient and even if she’s nineteen and she’s better at CAMHS leave her. If she’s sixteen and needs to be at adult services move her, stop the rigid lines deal with the person who’s ill.” (David, P26:L16)

In relation to the timing of transitions, the central issue reported by participants was the need for greater flexibility in the eligibility criteria for services and how decisions are determined. The use of chronological age was seen as a poor proxy for decisions based upon an assessment of the ‘goodness of fit’ between the service and the developmental needs of the individual.

Feelings about transition

Most participants described the process of transition as fearful. Words such as nervous, worried, frightened and scared were repeated throughout the interviews. Participants spoke of several factors contributing to feelings of fear associated with the transition to AMHS. These included; loss of relationships with familiar clinicians, a lack of clarity regarding the input that would be provided by AMHS, lack of familiarity with the new service, and the absence of clear plans for the transition. Several participants reported that they believed, or were told by clinicians in CAMHS, that AMHS would not provide the same level of service. This made the prospect of transition particularly anxiety provoking, as articulated by Donna amongst others:

“I was, was quite nervous and I was quite, I suppose I was quite worried that I wouldn’t get as much support because you always think that children get looked after better than adults, whereas when you’re out in the adult service you wouldn’t get looked after as well.” (Donna, P11:L5)

Two service users who were receiving treatment in in-patient settings prior to their transition to AMHS, also spoke of fears associated with the loss of structure and boundaries provided by the hospital environment:

“Well like I said. I didn’t know what the treatment was going to be and I thought that maybe because I was coming home there obviously wouldn’t be as much boundaries so I thought I was maybe going to go like more unwell... I was really scared.” (Fiona, P6:L19)

A somewhat divergent view was expressed by two service users, Elaine and Becky. Both women reported feeling dissatisfied with the input they received from CAMHS and expressed hopeful trepidation about the move to adult services. Twenty-year-old Elaine described how she hoped that clinicians in adult services would have more expertise, or adopt a different approach to treatment:

“I think I was quite nervous... but at the same time I was maybe a bit more hopeful that, I just thought maybe they’ll know what they’re doing and will give me something different that I’ve not tried” (Elaine, P8:L27)

For carers, an additional factor that contributed to fears about the transition was exclusion from, or limited involvement in, preparations for this. The following quote from Audrey, a mother of two in her mid-forties, suggests that limited communication about the plans for her daughter’s transition contributed to feelings of uncertainty and confusion:

Audrey: *"It was just like going into the unknown all the time. Nobody explained anything... 'you're passed on to this person now' or 'you're going here'. I think that was quite hard... going in and like starting again, not knowing anybody and I think maybe if we had a couple of meetings or something before she was discharged to meet people it wouldn't be so bad or so hard."*

Interviewer: *"Uh hu, how did it make you feel?"*

Audrey: *"Quite nervous and worried"* (Audrey, P27:L8)

The prominent emotion associated with the process of transition amongst service users and carers was fear. It was notable that this was described as a fearful experience both by those who reported involvement in plans for transition and those who did not. However, where preparations for transition were built into the process this helped to alleviate some of these anxieties, as discussed previously. Where there was a lack of information or, in some cases perhaps, misinformation about the input that would be received in AMHS this clearly contributed to anxieties. For carers, a lack of communication regarding plans for transition added to fears about this process. However, for participants who perceived their experience in CAMHS negatively, the prospect of transition was associated with hope that they may have a better experience in adult services.

Theme 2: Shift in Treatment Ethos

The shift in treatment ethos between CAMHS and AMHS was discussed by all participants. Participants' reflections on the shift in treatment incorporated three themes: autonomy, confidentiality and change in treatment approach.

Autonomy

The concept of autonomy stems from the Greek origin of the word meaning 'self-rule' and 'self-determination' ⁴⁰. In the current study this term is used to reflect the capacity to make choices about one's treatment and to understand the implications of these choices.

The shift in approach to treatment towards service users having greater involvement in decision-making and taking on more responsibility was remarked on by all service users. Most service users perceived this change positively. There was a tendency to contrast the more directive approach to treatment experienced in CAMHS with more collaborative approaches adopted in AMHS. Claire described how she more readily accepted this approach to treatment:

"I think it's not as much, it's not forceful here but it's not 'you must do this or that' it's what you want to do... I accepted it better." (Claire, P19:L3)

A number of service users also spoke of an increased focus on their developing understanding of their illness within adult services, which helped them to accept responsibility for treatment. This point was elaborated upon by Donna:

"I did kinda feel like decisions were made for you in CAMHS and you kinda had to go along with it and nothing was explained in terms of how it was going to help you or how ... I think you probably never understood how bad the illness could be I think that it was just kinda like, 'You're not well and we're telling you you're not well and this is what you have to do', whereas when you moved into the adult services there was more focus on trying to understand what the illness was and in turn that helps you to deal with it and accept you are really ill." (Donna, P5:L1)

This aspect of the shift in treatment ethos was only remarked upon by two carers. In both accounts the views expressed were congruent with those abovementioned.

Audrey described how she perceived these changes to have benefitted her daughter:

“I think that’s what Freya needed. Someone to actually listen to what she was saying... and work ways around to help her, which she thought would be helpful rather than what they thought would be helpful... I think they’re good that way... rather than having demands.” (Audrey, P19:L15)

Some service users indicated that they experienced difficulties taking on more autonomous role in treatment, as was expected within AMHS. The following quote from twenty-year-old Elaine suggests that she struggled with this:

“I know that like you’re an adult and you’re supposed to take responsibility for yourself but then you maybe can’t.” (Elaine, P10:L36)

This issue was also reflected upon by Elaine’s parent, who stated that her daughter would like someone else to take responsibility for her eating. This point was extended further by eighteen-year-old Amy. Amy’s use of language conveys a sense of ambivalence about treatment suggesting that it was difficult for her to accept treatment but she almost wished to be compelled to do so:

“It was a bit hard because they kind of just turned around and said ‘You’re eighteen now so all of the decisions are up to you’. I don’t like decisions at the best of times but when it’s... I’m also caught up in all my thoughts or whatever and my thoughts are saying ‘don’t go back because you can then do what you want’ or whatever then at the same time I want help and you just don’t know. You kind of just want someone to make that decision but they’re not going to do it for you.” (Amy, P12:L6)

A number of carers’ described how they modified their approach to supporting their loved one, in line with the shift in treatment approach. There was a parallel with

normative changes in parent-child relationships as children reach adulthood, with parents moving from a more directive approach to an encouraging and facilitative stance. This is illustrated by the following quote from Erica, a working mother of two:

“You know increasingly now it’s up to you Jane. I will guide you, I will try my utmost, but in the end it’s up to you.” (Erica, P19:L15)

For carers there were both pros and cons to this change in role, as reflected in a statement from Barbara:

“Well it’s good that you’re not I suppose being the baddy ... but at the same time if I was feeding her she’s be eating more.” (Barbara, P38:L44)

Most service users valued the opportunity to have increased control over decisions about their treatment. However, some experienced difficulties with this change in role. The service users who struggled to accept these new responsibilities conveyed a greater sense of ambivalence about engaging in treatment, and appeared to have an external locus of control in relation to this. Delayed development of maturity also appeared to contribute to these difficulties.

Where discussed by carers, there was congruence within parent-child dyads on this topic, indicating that parents’ were insightful about what this shift in treatment approach meant to their daughters’. From a carers perspective there was recognition the move to adult services also necessitated a shift in how they supported their loved ones.

Confidentiality

For most participants the move to AMHS heralded the introduction of confidentiality. However, in some cases confidentiality was implemented in CAMHS once the service user turned sixteen.

Most service users discussed how their parent's role in treatment changed following the implementation of confidentiality. There were mixed views on the benefits of this. For some service users, such as Becky, this was viewed favourably:

"I just prefer it. I just prefer to like deal with it myself em like she's [Mother] still like aware of like what's going on. I do kind of tell her things but she's just not as, she's just not got as big a role as she did at CAMHS." (Becky, P10:L1)

Others indicated that there were both pros and cons to confidentiality. The service users who experienced difficulties adopting a more autonomous role within treatment, indicated that confidentiality to some extent maintained secretive aspects of their eating disorders. The following quote from Elaine conveys a sense of tension between her desire for confidentiality and insight that this may not be beneficial:

Elaine: *"I wanted everything confidential so I kept a lot of it to myself."*

Interviewer: *"Uh hu, and how was it for you to have that change?"*

Elaine: *"I felt better with it, but it's kind of part of the illness. I still do the same thing I keep all that side of things to myself and just tell mum just to stay out of it. So I don't know, I kind of, I think in a way it's helpful but in a way I can see what it's not to the same extent."* (Elaine, P3:L40)

Confidentiality was a very salient and emotive issue for carers. All carers discussed the resultant change in their role in their daughters' care and difficulties associated with this. All carers indicated that they were less involved in treatment and received less information from services. Barbara provided an account of how she continued to support her daughter to attend appointments but no longer had any knowledge of her treatment:

"It was, it was difficult and when Aislinn turned sixteen and you were told nothing it became even more difficult because I didn't know her weight, I didn't really know

what her treatment plan was, I just picked her up at school and took her to every appointment they told me to take her to, and sat in the waiting room.” (Barbara, P7:L2)

All carers indicated that exclusion from treatment significantly contributed to their concerns and worries, adding to difficulties associated with the caregiving role. This was particularly difficult for carers whose loved ones remained unwell. The majority of carers expressed a desire for more involvement in treatment, so that they would be included in decision-making, notified of important information and could provide information to services. On the other hand, most carers acknowledged that confidentiality was important from a service user’s perspective to foster trust with clinicians and the development of autonomy. David articulated the predicament created for services by the opposing needs of service users and carers:

“I totally understand that confidentiality aspect although I don’t totally agree with it. I think that is always going to be the barrier. The first duty of the... team is their duty to my daughter, which is correct and it just so clashes with what our needs are. I think that sums it up and that will always be.” (David, P40:L29)

Where AMHS clinicians established relationships with carers and retained open lines of communication, within the boundaries of confidentiality, this helped to allay carers concerns somewhat. A number of carers spoke of clinicians being accessible and contactable should they have concerns, although frustration about the lack of information remained an issue for some. Audrey, described how the knowledge that she could express concerns to clinicians in AMHS helped to reduce her stress:

“I think the stress has been took a wee bit off me, with knowing that I can phone up and say... ‘Freya is really struggling, she’ll probably not tell you this but...’ and they’d say ‘well we’ll talk to her about it.’” (Audrey, P23:L10)

Where carers felt excluded by AMHS or did not have any communication with clinicians, they found it difficult to know where to turn if they had concerns about their loved one. Cathy conveyed a sense of feeling lost and not knowing how to help her daughter access support:

“It’s really difficult cause I can see at times that she’s not doing well and then there are some times where she’ll say ‘ I need help mum but I don’t know where to go or I don’t know what to do’ and I don’t know what to do either.” (Cathy, P15:L1)

A number of carers highlighted that they did not have adequate preparation about how their role would change following the transition to AMHS, and that this should be discussed more in the lead up to the transition. The lack of preparation for this change left some carers with uncertainties about their rights:

“I would hope that if there was a concern that [the dietician] would contact me but I don’t know. I don’t know if she can without asking Jane if she can contact me. So to me there are grey areas as to exactly my rights now.” (Erica, P11:L11)

Confidentiality was a very important issue for carers but appeared less so for service users. Most service users chose to share only limited information with their parents. However, they had mixed views on the benefits of this with some service users indicating that this may contribute to secretive aspects of their eating disorder. Carers unanimously reported that the difficulties accessing information about their loved ones treatment following the implementation of confidentiality contributed to their worries and concerns. However, where AMHS clinicians developed relationships with carers and maintained open lines of communication to enable carers to express concerns, this helped to alleviate some of these concerns. Some carers were unclear of their rights and it was suggested that carers would benefit from greater preparation for how their role in treatment may change in AMHS.

Change in treatment approach

In line with the changes outlined in the preceding sections, all participants described a shift from a family based approach to treatment to a more individual approach. Service users tended to compare their experiences of treatment in CAMHS and AMHS. All service users described difficulties expressing themselves during family sessions in CAMHS. Several factors contributed to this included feelings of guilt, fear of parental anger or disapproval, and shyness. Most service users expressed a dislike of family sessions and some described them as distressing. Becky described how she found it difficult to speak freely within family sessions, contrasting this to her experience in AMHS:

“I think in CAMHS like em because my mum was there a lot of the time I didn’t really like, I probably wasn’t as honest as I should have been because like, like I knew that she’s like get angry and stuff but at the adult service I can just kinda be honest. There were just certain things I just didn’t want, like I didn’t feel comfortable saying in front of my mum.” (Becky, P13:L6)

Only one service user spoke more positively of her experience of family sessions. It was notable that this woman reported having individual sessions first and only starting family sessions latterly in CAMHS. This differed from the accounts of other service users. Amy described how, although family sessions were difficult, they helped to facilitate better communication within her family:

Interviewer: *“How did you feel about your family’s involvement in the treatment?”*

Amy: “A bit mixed. Sometimes I wanted to hide it all from them and like, yeah so I could get away with things but at the same time I wanted someone to be there and to understand – someone I could talk to at home and stuff. Our communication

was not there and the family therapy then helped us open-up a bit more to each other.” (Amy, P3:L5)

This notwithstanding, all service users described individual sessions as preferable to family sessions. The majority of service users indicated that individual sessions provided an opportunity for them to open-up about their thoughts and feelings. The following quote from Fiona portrays how she developed her voice within individual sessions:

“I felt as if I could speak more. Like I could say how I was feeling and maybe reasons why I was being sick or doing what I was doing... it took me a good few years to open up”(Fiona, P11:L32)

Some service users indicated that they felt it would be helpful to continue to have family sessions alongside individual sessions in AMHS, as family sessions were considered to help communication. This point was articulated by Claire:

“It was better [less parental involvement] but I think they needed to be more involved so they knew what was going on as well, cause it’s hard to go home and say things, there were some things that if they were told then it was easier... I think some individual but some family as opposed to just no family.” (Claire, P18:L28)

While the majority of carers expressed a desire for more involvement in treatment, carers view on family based approaches differed. Some indicated that they found family therapy helpful:

“We started family therapy all together... we found that very positive” (Erica, P5:L5)

However, for others family therapy was experienced as intrusive:

“I feel we were, analysed inside out” (Cathy, P3:L17).

In cases where carers reported that a family based approach to treatment was adopted within CAMHS, the majority of carers indicated that they did not have the required support to implement this within the home:

“If there’s gonna be a treatment model of family therapy and family, the home is the place where they get better they need to put more support workers in. It doesn’t even need to be every day. If my wife and I had known that on a Wednesday we’d get a day off it that would have got us through the Thursday, Friday, Saturday.” (David, P50:L2)

There was no consensus on how carers would like their involvement in treatment to be increased beyond greater information sharing, as outlined in the previous section. However, all but one carer described some form of involvement with AMHS. A number of different forms of involvement with AMHS were described such as attending review meetings, provision of information about eating disorders, attending education sessions or having sessions with clinicians, either individually for support or with their loved one. These were generally perceived as helpful. The more involvement with AMHS that carers described the more positively they tended to speak of this. Cathy described attending carers information sessions:

Cathy: “I came to carers meetings last year. They did six carers meetings like for husbands, wives, mothers, dads or whatever. So I came to they meetings and em a couple of them did those meetings, like the team had they meetings but that wasn’t specific to Tina that was just like generally how to cope and generally how to deal with a person with an eating disorder.”

Interviewer: *“And how did you find those sessions?”*

Cathy: “Yeah, I really enjoyed it.” (Cathy, P15:L23)

All participants experienced a more individual based approach to treatment following the transition to AMHS. Service users expressed a preference for individual sessions over family sessions, with the majority indicating that it was easier to open up about their thoughts and feelings on an individual basis. All service users spoke of difficulties with self-expression during family sessions in CAMHS and most expressed a dislike of these sessions. However, some service users reported that family session helped to improve communication within the family, and that the continuation of these alongside individual sessions in AMHS would be helpful. Carers had mixed experiences of family based approaches to interventions. Some perceived them as helpful while others did not. Although carers expressed a desire to be more involved in treatment there was no clear consensus about what this would entail. The majority of carers reported that they had some form of involvement with AMHS, while this took different forms, any type of information, support or involvement in treatment was generally considered helpful.

Theme 3: Outcome of Transition

All participants discussed how the experience of transition from CAMHS to AMHS impacted upon them or their loved one. There was considerable variation in participant's account of the outcomes of transition. Three themes formed this super-ordinate theme: *development, disruption, no difference*.

Development

A number of service users and carers spoke of positive developments following the transition to AMHS. Several participants spoke of how they or their loved one developed increased insight into their illness following their transition to AMHS. Participants related this to the increased focus on developing understanding within

AMHS, having the opportunity to open up within individual sessions and access to specialist services. Becky described how she now has a better understanding of her eating disorder:

“I think at CAMHS they didn’t really, like we never really looked into like why it started and I think but now I can understand why it all kind of started but I didn’t really like, I don’t, I don’t know like it just didn’t really make sense but now it makes more sense.” (Becky, P3:L13)

Similarly, David spoke of psycho-educational and therapeutic work undertaken with his daughter in AMHS, and how this helped her to develop insight into her illness:

“I think even from some of the stuff she’s found out about diet and what food does for you and to the work they’ve tried to do about body image. Em, you know I think that she has got quite a good insight into her illness now.” (David, P47:L28)

Some service users spoke of developing better relationships with clinicians in AMHS or becoming more engaged with services. This was also remarked upon by one carer. Within the interviews it appeared that this was related to improved communication and more collaborative relationships with clinicians. Fiona described the positive therapeutic relationship she developed with a clinician in AMHS:

“She [clinician] was quite hard on me but we got on really well and like we would have a laugh and that would keep me a wee bit upbeat and... but I think the relationship like that we had was really really helpful.” (Fiona, P10:L29)

Audrey reflected on how the development of positive relationships and communication with clinicians helped her daughter to make progress:

“I think she’s come on leaps and bounds since she came to adult services. She seemed to be more em... I think she seemed to like the staff more up here. She seemed to communicate with them.” (Audrey, P15:L25)

Some carers discussed how they felt the transition to adult service had helped their loved one to become more independent. Erica described how her daughter lacked confidence in her ability to act autonomously, but as a result of the shift in treatment ethos in adult services she was being slowly gaining in confidence:

“They’ve said... right you’re kind of more on your own and she’s thought, ‘right, ok I can do this actually’ and all the while she’s thinking ‘I don’t know if I... oh I did do it, oh I did it I managed’.” (Erica, P19:L4)

Participants discussed a number of key areas of development including increased insight, better relationships with clinicians, increased engagement with services and increased independence. It appeared that these changes helped to facilitate progress for some of the service users, with two individuals being described as in recovery.

Disruption

For some participants the transition between CAMHS and AMHS resulted in a disruption of care, which negatively impacted on service user outcomes. This was related to gaps in service provision and discrepancies between level of service user needs and the level of input provided. Claire spoke of how the adult service she was transitioned to failed to provide the level of support she needed to maintain progress achieved as an inpatient:

“I think at that point, if I’d come out and I could have come somewhere like here [Eating Disorder Service] I don’t think I would have had to go back in as ill as I was... Cause I was doing well but then they just... through not having any meal support or anything it just... and going to someone to get weighed wasn’t really doing anything for it so.” (Claire, P11:L22)

Cathy appraised the impact of her daughter's transition as having been detrimental to her recovery:

Interviewer: *"Do you feel that the experience of moving between services has had any impact on Tina?"*

Cathy: *"I think it's been detrimental to her recovery. I definitely do. There has been no continuity and no... gaps everywhere."* (Cathy, P21:L12)

Another disruption experienced by participants was disruption of relational continuity. The transition from CAMHS to AMHS necessitated a change in clinical team for all participants. However, in a minority of cases, participants had a clinician who remained with them throughout their journey of care. How participants perceived the change in their clinical team following transition was, to a large extent, dependent on the nature of their relationships with CAMHS clinicians and subsequently with AMHS clinicians. The termination of relationships due to transition was more disruptive where trusting therapeutic relationships had been established. Amy spoke positively of her relationship with the psychologist at CAMHS and conveyed a sense of loss at the ending of this relationship:

"I had known [my psychologist] for four years or so and I got on really, really well with her and I didn't really understand why my age meant I had to really change people but... just the way it is." (Amy, P10:L13)

It was notable that participants not only experienced disruptions in relationships as a result of the transition between services, some participants also experienced changes in clinicians due to staff turn-over or sickness. In a few cases, service users experienced the loss of several key clinicians, in addition to transition related changes. Several participants spoke of difficulties 'starting again'. The difficulties associated with the disruption of relational continuity are clearly articulated by Claire:

“Even with like therapists that I seen, I seen about four or five, which I always find hard and still do cause you build up trust with somebody and then they disappear and you have to start all over again with the simple questions of when did it start, how did it... and all that.” (Claire, P6:L8)

Participants discussed two key types of disruption that they experienced as a result of transition. These were disruption of care and disruption of relational continuity. Where participants described disruptions of care, these were reported to have negatively impacted on service user outcomes. The impact of disruptions of relationship continuity was most significant for those who lost positive therapeutic relationships with CAMHS clinicians or who experienced multiple changes of clinicians.

No Difference

Some service users and carers indicated that they felt the transition from CAMHS had neither a positive nor a negative impact. In these accounts participants generally conveyed that personal readiness to change was more pertinent than changes in service or intervention approach. The importance of personal readiness to change is illustrated in the following quote from Elaine:

Interviewer: *“Do you feel that the process of moving from the child service to the adult service has had any impact on your eating disorder?”*

Elaine: *“I don’t think so, I think what would happen would happen. If your mind is not in the right place to, you’re not ready to change then you wouldn’t.” (Elaine, P17:L15)*

Erica indicated that she was unsure whether her daughter felt the move to adult services resulted in her receiving less support but similar to Elaine her use of language conveyed a sense that ‘what would happen would happen’:

“I don’t know, I think her battle goes on and whether had she stayed on in the adolescent it would be the same the battle carried on, whether she perceived there is less support, she is more on her own I don’t know.” (Erica, P18:L40)

Interestingly, one carer described how she and her daughter had differing opinions on what helped to facilitate her process of recovery. Audrey indicated that she perceived that the nature of support her daughter received from a specialist service to have facilitated her progress, while her daughter more so emphasised her personal readiness to change:

“I think she should have got put here [eating disorders service] first, she wouldn’t have maybe had that journey of being ill all that length of time ... Then when I say that to Freya she says ‘I’ve not wanted to change then’” (Audrey, P17:L20)

Within the interviews the language used by service users frequently reflected the Transtheoretical Model of Behaviour Change ^{41,42}, with individuals describing pre-contemplation, contemplation, resistance, ambivalence, decisional balance, action and relapse. For some service users the changes described in theme two seemed to facilitate a progression towards action but others remained at an earlier stage of change. Several participants indicated that personal readiness to change was more pertinent than changes in services or intervention approach, thus the transition was not considered to have had a significant impact on service user outcomes.

DISCUSSION

The aim of this study was to explore the transition between CAMHS and AMHS from the perspectives of both young people with eating disorders and carers who had been through this process. Participants appeared motivated to discuss their experiences of the transitional care. All but one interview lasted over 30 minutes, with the majority of carers' interviews extending to over an hour, suggesting that participants were interested in discussing this topic.

The data collection revealed a greater level of information about transitions than was expected, covering those between CAMHS and AMHS, and within tiers of service provision. The complexity of transition experiences meant that it was difficult for some participants to consider their experiences and feelings about the transition from CAMHS and AMHS in isolation from other transitions. Therefore, aspects of other transitions were inevitably incorporated within the data. Although unintended, this helped to identify broader issues related to the experience of transition.

Three superordinate themes were identified: 'Transition Experience', 'Shift in Treatment Ethos' and 'Outcome of Transition'. Although each theme was distinct in its own right, many of the participants indicated that 'Transition Experience' or 'Shift in Treatment Ethos' impacted upon the 'Outcome of Transition'. A visual representation of this is illustrated in Figure 1 (page 56).

There was generally a high degree of concordance between the accounts of services users and carers. However, some themes were more pertinent for one group than the other, and views on the shift in treatment ethos differed somewhat between groups. Other studies have identified that the views of individuals with eating disorders and their relatives are largely similar^{43,44}.

Transition Experience: The first theme explored participants' experiences and feelings about the process and timing of transition. The prospect of transition from CAMHS to AMHS was associated with feelings of fear or anxiety for most participants. Several factors contribute to anxieties about the transition, including the loss of familiar relationships, uncertainty about AMHS and the absence of clear plans for the transition. Similar anxieties about transition to AMHS have been identified amongst young people with mental health problems and their carers ^{18,45}.

Most service users had some form of preparation for the transition from CAMHS to AMHS, but carers were involved to a lesser degree. Transition plans that included several elements to help prepare participants for transition and ensure continuity of care were considered most beneficial. Where participants reported an absence of transition planning, it appeared that disruptions of care were more likely to occur. This is consistent with findings from studies of user perspectives on transitional care in physical health ^{46,47} and mental health ^{18,45}. These findings are also in line with the recommendations of recent guidelines and policies on transitional care which emphasise the importance of a planned and coordinated transition process ^{14–17,19}.

Being involved in plans and preparations for transition helped to alleviate some of the anxieties experienced by service users and carers. Where there was limited involvement in plans for transition, or communication regarding the transition, the converse was true. This was a more notable difficulty for carers, as they were less likely to be included in transition planning. Singh et al. ¹⁸ noted that attending transition planning meetings helped to allay parental concerns about transition. However, in contrast to the current study, it was reported that at least one parent attended transition planning meetings in most cases ¹⁸. Thus, it may be that young

people with eating disorders are more reluctant to have parental involvement in their care than young people with other mental health problems.

All service users and carers reported that age-based criteria were used to determine the timing of transition. This resulted in service users receiving treatment at services that they did not perceive to be suited to their developmental needs. The need for more flexibility in the eligibility criteria for services and how decisions are determined was highlighted by participants. The experiences of participants in the current study are in contrast to the approach delineated with recent policies and guidelines, which advocate that the transition from child to adult services should be viewed as a flexible process, determined by individual needs^{14–17,19,20}. Other studies of service user perspectives on transitional care have also highlighted the need for transition to be based on individual readiness and developmental maturity^{46,47}.

Reports on transitional care in eating disorders have highlighted that fears of maturity, and delayed emotional or intellectual development as a result of illness, require additional consideration when managing transition to AMHS for young people with eating disorders^{23,29}. While this issue was evident for one of the service users in the current study, service users more commonly reported feeling the treatment approach in CAMHS was not age-appropriate. Indeed a number of service users indicated that they would have chosen to transfer to adult services earlier.

Shift in Treatment Ethos: The second theme offers a framework for understanding how service users and carers experience the differences between CAMHS and AMHS. There were some similarities with other studies of transitional care in physical health and mental health.

In line with previous reports, most service users valued the opportunity to have increased control over decisions about their treatment^{18,47}. However, some service

users struggled with the expectation that they should assume a more autonomous role in treatment, and wished others to retain responsibility for decision-making. It may be that some young people had the developmental maturity to cope with these changes, while others did not. This fits with the recommendation that a gradual introduction of an 'adult like approach' may be required for young people who have fears of maturity or delayed development in other domains²³. Other studies have identified that complete control over treatment is not deemed desirable by individuals with eating disorders ^{48,49}. A combination of autonomy and direction has been reported as the most successful approach, balancing service users needs for guidance and control ⁴⁹. This would be consistent with the needs expressed by service users in the current study.

Service users perceived the approach to treatment in AMHS to be more collaborative than CAMHS, with an increased emphasis on developing their understanding of their illness. Most service users perceived these changes positively. This is in line with findings that individuals with eating disorders rate collaborative approaches as more acceptable than directive approaches ⁵⁰, and value treatments that focus on issues underlying the eating disorder ⁵¹⁻⁵⁴.

For most participants, the move to adult services and implementation of confidentiality occurred concurrently. Following this move, carer involvement with services was more limited, and many reported difficulty accessing information about their loved ones' treatment. Exclusion from treatment greatly contributed to carers worries and concerns. These findings concur with previous studies of carer perspectives in the areas of mental health ¹⁸ and eating disorders ²⁴.

Carers in the current study found it particularly difficult when they had no point of contact in AMHS, and felt unable to express their concerns. This difficulty was

also reported by parents of individuals with mental health problems in a study on transitional care ¹⁸. However, where open channels of communication were maintained between carers and AMHS clinicians, this helped to alleviate some of these worries. It was also evident that some carers were unclear about their rights and would benefit from greater preparation for the change in their role in treatment. The needs identified by carers in the current study support the recommendations for carer education, and preparation for transition, outlined in guidelines for transitional care ¹⁷.

Most service users chose to limit their parents' involvement in treatment following the move to adult services. However, there were mixed opinions on the benefits of this. In accordance with the findings from studies of young people with mental health problems ⁴⁵, some service users preferred not having parental involvement in their care. However, others indicated that while they desired confidentiality this was related to, and potentially contributed to, secretive eating disordered behaviour. This issue has not been identified in other literature on transitional care and may be unique to eating disorders.

In CAMHS the family unit was most commonly the forum for therapy, while in AMHS service users received therapy on an individual basis. Service users expressed a preference for individual sessions over family sessions. The majority of service users indicated that it was easier for them to express their thoughts and feelings in individual sessions. By contrast, service users described difficulties with self-expression during family sessions and some reported finding these sessions distressing. Difficulties with emotional expression in eating disorders have been reported in the literature ^{6,43,55}. This would appear relevant to the difficulties service users described with emotional expression in family sessions. It was notable that

where individual therapy was provided first, family therapy was considered more helpful by the service user.

Carers expressed a desire to be more involved in treatment, as has been found in other studies of transitional care ¹⁸ and carer perspectives in eating disorders ^{24,27,28,56,57}. Where carers reported that they received information, support, or had some involvement in treatment in AMHS, this was considered helpful. This is in line with national guidelines on the treatment of eating disorders, which recommend that services should involve carers and family members, and offer support and education ²¹. The continuation of family involvement is also recommended within clinical guidelines on transitional care in eating disorders ^{23,29}, and information sharing is considered vital in cases with significant medical risks ³⁰. However, the challenge of balancing this with confidentiality is acknowledged ^{21,30,58}.

Outcome of transition: The third theme explored the range of outcomes of transition reported by participants. These included Positive Developments, Disruptions, and No Notable Differences.

Participants discussed a number of positive developments as a result of their move to adult services. These included increased insight, better relationships with clinicians, increased engagement with services and increased independence. These positive developments appeared to be related to the change in treatment ethos in adult services, as discussed in the above section. The importance of the therapeutic alliance ⁵³ and effective communication ⁴⁹ has been highlighted in previous qualitative studies in eating disorders. Increased independence has also been reported as an outcome of transition in mental health, and in most cases young people felt that their mental health improved following transition ¹⁸. It was notable that the majority of participants in the current study received treatment within

'generic' CAMHS and then moved to 'specialist' AMHS. Most participants felt that 'specialist' clinicians had a better understanding of eating disorders and valued their expertise, which may also have contributed to positive developments following transition.

Participants discussed two key types of disruption that they experienced as a result of transition: disruption of care and disruption of relational continuity. Where participants described disruptions of care this appeared to relate to poorly planned transitions, with gaps in service provision or an inadequate level of input following transition. This negatively impacted on service user outcomes. These findings concur with reports in the areas of physical health ¹⁴ and mental health ¹⁸ that a disruption of care during transition can negatively impact health and well-being.

Disruptions of relationship continuity were most significant where positive therapeutic relationships with CAMHS clinicians were terminated following transition, or where service users experienced multiple changes of clinicians. It was difficult for service users to develop trusting therapeutic relationships, and so the impact of losing these, once established, was considerable. Carers also commented on difficulties involved in changing teams and 'starting again'. The issue of relational continuity was also identified by Singh et al. ¹⁸ in their study on transitional care in mental health. Participants indicated a desire for more flexibility in relation to continuing relationships with clinicians with whom they had established relationships.

Some participants indicated personal readiness to change was the most important determinant of outcome, therefore that impact of transition was perceived neutrally. Readiness to change is considered to be an important construct in eating disorders ^{8,59,60}. Studies exploring service user perspectives on recovery in eating disorders have identified internal motivation to change or 'stage of change' as a key

factor in recovery^{51,61}. Research has also been shown readiness to change to be predictive of clinical outcome including dropout from treatment, symptom change, maintenance of changes at follow-up and relapse^{62,63}.

CONCLUSIONS

Research on service user and carer perspectives has been relatively neglected within the field of eating disorders⁶⁴. There is limited knowledge of service user and carer experiences of treatment and pathways of care³³. To our knowledge, this is the first study to explore the experience of transitional care from the perspectives of young people with eating disorders and their carers.

For most service users and carers the transition from CAMHS to AMHS was associated with feelings of fear and anxiety. Transitions that were planned and coordinated provided the best continuity of care, while an absence of transition planning was associated with disruptions of care and negative outcomes. Both service users and carers desired more involvement in transition planning and decision making. They called for more flexibility in the eligibility criteria for services and timing of transition, highlighting the need for this to be determined on an individual basis taking account of developmental needs.

Differences in treatment approach between CAMHS and AMHS were explored. Service users experienced increased autonomy in AMHS. While most service users viewed this change favourably, some struggled with the expectation to take more responsibility within treatment. Service users favoured the use of individual therapeutic approaches in AMHS. This provided them with a forum for expression of thoughts and feeling, which they found more difficult in family therapy.

Carer involvement in treatment was limited in AMHS due to the implementation of confidentiality. This significantly added to parental worries and concerns. However, where AMHS established open channels of communication with carers, this helped to address some of these concerns. Service users had mixed views on the benefits of confidentiality and in some cases it appeared that, while desired, confidentiality perpetuated secretive eating disordered behaviour.

Participants reported a range of outcomes of transition ranging from positive, through neutral, to negative. Positive outcomes included: increased insight, better relationships with clinicians, increased engagement with services and increased independence. Negative outcomes were associated with disruption of care and disruption of relational continuity. Where participants considered the outcome of transition as more neutral, personal readiness to change was deemed a more important determinant of outcome.

In light of these findings it is important to consider the role of the Transtheoretical Model of Behaviour Change ^{41,42} in psychological treatment for young people with eating disorders. Given the potential functions that eating disorders may serve, many individuals are ambivalent about changing eating disordered behaviour. It is recognised that when an individual is at the precontemplative or contemplative stage of change, directive approaches or advice on how to change may lead to resistance, drop out from treatment, or even symptom escalation ^{65,66}. An awareness of the stages of change model can enable clinicians to match their intervention to the service users readiness status and apply specific motivation enhancement techniques to encourage change, such as exploring the costs and benefits of change ⁶⁷.

In the current study, service users valued the opportunity to explore their difficulties and develop their understanding of their condition, within collaborative therapeutic relationships. This is in keeping with the ethos of motivational approaches⁵⁰, and for some service users this approach facilitated a move towards the preparation, action and maintenance stages of change. Service users were more resistant to directive approaches, the primary focus of which appeared to be weight restoration. This suggests that there was a mismatch between the intervention and the service users' stage of change^{50,67}.

The establishment of non-negotiable goals regarding nutritional intake are a vital component of treatment for eating disorders. It would appear that the manner in which this is implemented has a significant impact on service users' engagement in treatment. A collaborative approach to treatment that combines firmness with respect, acknowledging an individual's readiness status and anxieties about change, while assisting them to set realistic goals regarding nutrition and other aspect of treatment would seem most appropriate to meeting the needs of young people with eating disorders^{50,54,66}. These findings have important implications for services and clinicians involved in the care of young people with eating disorders.

Clinical Implications

Clinical guidelines for transitional care in mental health⁴⁵ and eating disorders^{29,23} have been proposed by a number of authors. These authors have highlighted several principles that are considered to facilitate the management of the transition process and ensure continuity of care. The current study by the use of IPA has enabled us to further elaborate these principles, and has added depth to the understanding of the importance of these principles in the area of eating disorders:

- **Timing:** Transition planning should start at least 6 months before the intended transfer date, and should not occur during a period of instability. An information package should be developed to be shared with service users and carers prior to transition. This would include information about adult services, differences in service provision and approach to treatment, confidentiality and parental involvement. It would also be helpful to provide a list of contact numbers for adult services.
- **Flexibility:** The transition should be needs-led and flexible, with a primary concern for the patients' best interests. Singh et al.⁴⁵ have suggested an 'age window' rather than strict cut-off age for transition, leaving flexibility to determine the optimal time for transition based on the service users needs. Service users and carers should be involved in decision making about transition and provided with options related to this from the point at which transition would be possible. More flexibility in the criteria for accessing AMHS would also be important to consider. In cases where eating disorders develop in later adolescence the need for transition may be avoided, and service users may receive more age-appropriate care, by direct access to AMHS.
- **Close collaboration:** Providing opportunities to meet with new clinicians, joint working between services and parallel care are key elements of collaboration between services. The development of designated transition workers with posts split between CAMHS and AMHS has also been suggested by Singh et al.⁴⁵. These approaches would help to ensure continuity of care. There are also examples of eating disorder service in the UK that work with both children and adults, including one service with young people between the ages of 13 and 25³³. Such services would provide another way of addressing

transitional issues and would ensure greater relational continuity for service users and carers.

- Working philosophy: The gradual introduction of ‘an adult-like approach’ is suggested. However, it may be that this would underestimate the developmental maturity of some service users. Individual assessment of maturity and decision making abilities would help to provide service users with the appropriate balance of autonomy and direction in adult services.
- Working with carers: AMHS should continue to involve carers and family, offering support and education about eating disorders. Where service users are resistant to carer involvement, it remains important to establish open channels of communication with carers.

Two additional recommendations from the current study concern preparation for change and greater consideration of the use of individual therapeutic approaches within CAMHS.

- Preparation for change: Preparation for leaving CAMHS should address loss issues within relationships with clinicians. Motivational assessment to explore what stage of change a young person is currently at, and evaluate the pros and cons of moving to AMHS, would also be beneficial.
- Individual therapeutic approaches: The finding that family therapy was disliked by all services users and experienced as distressing by some, warrants greater consideration of the use of individual therapeutic approaches within CAMHS. While clinical guidelines for the treatment of AN in children and adolescents recommend family interventions ²¹, and these approaches have the strongest evidence base ^{68–71}, there is also evidence to support the use of

individual therapeutic approaches^{70,7221}. It appeared that individual sessions fostered skills in emotional expression which made the experience of family therapy easier at a later stage. Thus, services should consider the provision of individual sessions concurrently to, or prior to, family-based treatment.

Implications for Future Research

Further research is needed to fully understand the journey of care of young people with eating disorders. Future research could explore the multiple points of transition in more detail; this may be possible with a qualitative study using a smaller sample. Additionally, it would be helpful to understand the perspectives of CAMHS and AMHS clinicians supporting young people during the process of transition. Further investigation of service users' experiences of different therapeutic approaches would be helpful, particularly with regard to family-based versus adolescent focused treatments.

Strengths and Limitations

The current study has a number of strengths. This is the first study to explore the experience of transitional care in eating disorders from both a service user and carer point of view. The inclusion of both service users and carers enabled us to illuminate the experience of transition from different perspectives, helping to understand the similarities and differences in their needs for transitional care. Participants were recruited from a number of health board regions, thus the accounts of participants reflect a range of services and transition procedures.

A number of limitations must also be noted. The majority of participants received treatment within generic CAMHS and 'specialist' AMHS. As such, some of the reported changes in treatment ethos may relate to the level of specialism of the

service rather than differences between child and adult services per se. However, specialist eating disorder services for young people across the UK are scarce²⁹ so this may reflect typical experience of young people with eating disorders and their carers. No male service users were represented within the participants sample, nor were any identified in the potential pool of participants. Thus, we do not know if the findings from this study adequately represent their experiences of transitional care. Another consideration is that all participants were volunteers. It is possible that the characteristics of these individuals or their experiences may differ from those who chose not to participate.

References

1. Fairburn CG, Cooper Z, Shafran R. Cognitive behaviour therapy for eating disorders: a “transdiagnostic” theory and treatment. *Behaviour Research and Therapy*. 2003;41(5):509–28.
2. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders*. 4th ed. Washington D.C.: American Psychiatric Association; 1994.
3. Fairburn CG, Shafran R, Cooper Z. A cognitive behavioural theory of anorexia nervosa. *Behaviour Research and Therapy*. 1998;37:1–13.
4. Fairburn CG, Harrison PJ. Eating disorders. *Lancet*. 2003;361:407–17.
5. Lavender A, Schmidt U. Formulation in complex eating disorders. In: Tarrier N, editor. *Case Formulation in Cognitive Behaviour Therapy: The Treatment of Challenging and Complex Cases*. East Sussex: Routledge; 2006. p. 238–61.
6. Schmidt U, Treasure J. Anorexia nervosa: Valued and visible. A cognitive-interpersonal maintenance model and its implications for research and practice. *British Journal of Clinical Psychology*. 2006;45(3):343–66.
7. Serpell L, Treasure J, Teasdale J, Sullivan V. Anorexia nervosa: friend or foe? *International Journal of Eating Disorders*. 1999;25(2):177–86.
8. Cockell SJ, Geller J, Linden W. Decisional balance in anorexia nervosa: capitalizing on ambivalence. *European Eating Disorders Review* . 2003;11(2):75–89.
9. Royal College of Psychiatrists. *Eating disorders in the UK: policies for service development and training*. Report from the eating disorders special interest group. London: 2000.
10. Hoek H, van Hoeken D. Review of the prevalence and incidence of eating disorders. *International Journal of Eating Disorders*. 2003;34(4):383–96.
11. Papadopoulos FC, Ekblom A, Brandt L, Ekselius L. Excess mortality, causes of death and prognostic factors in anorexia nervosa. *The British Journal of Psychiatry*. 2009;194(1):10–7.
12. Steinhausen H-C. Outcomes of eating disorders. *Child and Adolescent Psychiatric Clinics of North America*. 2009;18(1):225–42.
13. Steinhausen H-C, Weber S. The outcome of bulimia nervosa: findings from one-quarter century of research. *The American Journal of Psychiatry*. 2009;166(12):1331–41.

14. Department of Health. Transition: Getting it right for young people – Improving the transition of young people with long term conditions from children's to adult health services. [Internet]. London: 2006. Available from: http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4132944
15. Kennedy I. Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs [Internet]. London: Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119445
16. Department of Health. Achieving equity and excellence for children [Internet]. London: 2010. Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119449
17. Royal College of Physicians of Edinburgh. Think transition: Developing the essential link between paediatric and adult care [Internet]. Edinburgh: 2008. Available from: <http://www.rcpe.ac.uk/clinical-standards/documents/transition.pdf>
18. Singh PS, Paul M, Islam Z, Weaver T, Kramer T, McLaren S, et al. Transition from CAHMS to Adult Mental Health Services (TRACK): A study of service organisation, policies, process and user and carer perspectives. Report for the National Institute for Health Research Service Delivery and Organisation programme [Internet]. Warwick: 2010. Available from: http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1613-117_V01.pdf
19. Vostanis P. Patients as parents and young people approaching adulthood: how should we manage the interface between mental health services for young people and adults? *Current Opinion in Psychiatry*. 2005;18(4):449–54.
20. Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM. Transition to adult health care for adolescents and young adults with chronic conditions. *Journal of Adolescent Health*. 2003;33(4):309–11.
21. National Collaborating Centre for Mental Health. Eating Disorders. Core Interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders. National Clinical Practice Guideline No. 9 [Internet]. London: 2004. Available from: <http://www.nice.org.uk/nicemedia/pdf/CG9FullGuideline.pdf>
22. Treasure J, Schmidt U, Hugo P. Mind the gap: service transition and interface problems for patients with eating disorders. *The British Journal of Psychiatry*. 2005;187:398–400.
23. Arcelus J, Bouman W, Morgan J. Treating young people with eating disorders: transition from child mental health to specialist adult eating disorder services. *European Eating Disorder Review*. 2008;16:30–6.

24. Winn S, Perkins S, Murray J, Murphy R, Schmidt U. A qualitative study of the experience of caring for a person with bulimia nervosa. Part 2: Carers' needs and experiences of services and other support. *International Journal of Eating Disorders*. 2004;36(3):269–79.
25. Perkins S, Winn S, Murray J, Murphy R, Schmidt U. A qualitative study of the experience of caring for a person with bulimia nervosa. Part 1: the emotional impact of caring. *International Journal of Eating Disorders*. 2004;36:256–68.
26. Highet N, Thompson M, King RM. The experience of living with a person with a eating disorder: the impact on the carers. *Eating disorders*. 2005;13:327–44.
27. Hillege S, Beale B, McMaster R. Impact of eating disorders on family life: individual parents' stories. *Journal of Clinical Nursing*. 2006;15:1016–22.
28. Tierney S. The treatment of adolescent anorexia nervosa: a qualitative study of the views of parents. *Eating Disorders*. 2005;13:369–79.
29. Arcelus J, Cashmore R. Child to adult: managing the transition. *British Journal of Healthcare Management*. 2008;14(12):9–14.
30. Treasure J, Whitaker W, Whitney J, Schmidt U. Working with families of adults with anorexia nervosa. *Journal of Family Therapy*. 2005 May;27(2):158–70
31. Department of Health. Putting people at the heart of care: The vision for public and patient experience and engagement in health and social care [Internet]. London: 2009. Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_106038
32. The Scottish Government. The Healthcare Quality Strategy for NHS Scotland [Internet]. Edinburgh: 2010. Available from: <http://www.scotland.gov.uk/Resource/Doc/311667/0098354.pdf>
33. Royal College of Psychiatrists section of Eating Disorders. Eating disorders in the UK: service distribution, service development and training. London: 2012.
34. Elliott R, Fischer CT, Rennie DL. Evolving guidelines for publication of qualitative research studies in psychology and related fields. *The British Journal of Clinical Psychology*. 1999;38:215–29.
35. Smith JA, Flowers P, Larkin M. *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: SAGE Publications; 2009.
36. Smith JA. Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*. 2004;1:38–54.
37. Willig C. *Introducing Qualitative Research in Psychology*. 2nd ed. Berkshire: McGraw-Hill Education; 2008.

38. Smith JA, Osborn M. Interpretative Phenomenological Analysis. In: Smith JA, editor. *Qualitative Psychology: A Practical Guide to Research Methods*. London: SAGE Publications.; 2003. p. 51–80.
39. Reid K, Flowers P, Larkin M. Explored lived experience. *The Psychologist*. 2005;18(1):20–3.
40. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. Sixth. New York: Oxford University Press; 2008.
41. Prochaska J, DiClemente C. *The transtheoretical approach: Crossing the traditional boundaries of therapy*. Florida: Krieger; 1984.
42. Prochaska J, Velicer W. The transtheoretical model of health behavior change. *American journal of health promotion*. 1997;12(1):38–48.
43. Kyriacou O, Easter a, Tchanturia K. Comparing views of patients, parents, and clinicians on emotions in anorexia: a qualitative study. *Journal of Health Psychology*. 2009;14(7):843–54.
44. Quiles M, Weinman J, TerolCantero MC, BeléndezVázquez M. The dissimilarity between patients' and relatives' perception of eating disorders and its relation to patient adjustment. *Journal of Health Psychology*. 2009;14(2):306–12.
45. Singh SP, Paul M, Ford T, Kramer T, Weaver T, McLaren S, et al. Process, outcome and experience of transition from child to adult mental healthcare: multiperspective study. *The British Journal of Psychiatry*. 2010;197(4):305–12.
46. Brumfield K, Lansbury G. Experiences of adolescents with cystic fibrosis during their transition from paediatric to adult health care: a qualitative study of young Australian adults. *Disability and Rehabilitation*. 2004;26(4):223–34.
47. Shaw K, Southwood T, McDonagh J. User perspectives of transitional care for adolescents with juvenile idiopathic arthritis. *Rheumatology*. 2004;43:770–8.
48. Tan J, Hope T, Stewart A, Fitzpatrick R. Attitudes of patients with anorexia nervosa to compulsory treatment and coercion. *International Journal of Law & Psychiatry*. 2003;26:627–45.
49. Reid M, Burr J, Williams S, Hammersley R. Eating Disorders Patients' Views on Their Disorders and on an Outpatient Service: A Qualitative Study. *Journal of Health Psychology*. 2008;13:956–60.
50. Geller J, Brown KE, Zaitsoff SL, Goodrich S, Hastings F. Collaborative versus directive interventions in the treatment of eating disorders: Implications for care providers. *Professional Psychology: Research and Practice*. 2003;34(4):406–13.

51. Federici A, Kaplan AS. The Patient's Account of Relapse and Recovery in Anorexia Nervosa: A Qualitative Study. *European Eating Disorders Review*. 2008;16:1–10.
52. Pettersen G, Rosenvinge JH. Improvement and Recovery from Eating Disorders: A Patient Perspective. *Eating Disorders*. 2002;10(1):61–71.
53. De la Rie SM, Noordenbos G, Donker MC, van Furth E. The Quality of Treatment of Eating Disorders: A Comparison of the Therapists' and the Patients' perspective. *International Journal of Eating Disorders*. 2008;41:307–17.
54. Geller J, Williams KD, Srikameswaran S. Clinician stance in the treatment of chronic eating disorders. *European Eating Disorders Review*. 2001;9(6):365–73.
55. Corstorphine E. Cognitive-Emotional-Behavioural Therapy for eating disorders: Working with beliefs about emotions. *European Eating Disorders Review*. 2006;14(6):448–61.
56. Graap H, Bleich S, Herbst F, Trostmann Y, Wancata J, De Zwaan M. The needs of carers of patients with anorexia and bulimia nervosa. *European Eating Disorders Review*. 2008;16:21–9.
57. Haigh R, Treasure J. Investigating the needs of carers in the area of eating disorders: development of the Carers' Needs Assessment Measure (CaNAM). *European Eating Disorders Review*. 2003;11:125–41.
58. NHS Quality Improvement Scotland. Eating Disorders in Scotland: Recommendations for Management and Treatment [Internet]. 2006. Available from: http://www.healthcareimprovementscotland.org/previous_resources/best_practice_statement/eating_disorders_in_scotland.aspx
59. Gale C, Holliday J, Troop NA, Serpell L, Treasure J. The pros and cons of change in individuals with eating disorders: A broader perspective. *International Journal of Eating Disorders*. 2006;39:394–403.
60. Geller J, Brown KE, Srikameswaran S. The efficacy of a brief motivational intervention for individuals with eating disorders: a randomized control trial. *The International journal of eating disorders*. 2011;44(6):497–505.
61. Keski-Rahkonen A, Tozzi F. The Process of Recovery in Eating Disorder Sufferers' Own Words: An Internet-Based Study. *International Journal of Eating Disorders*. 2005;37:S80–S86.
62. Geller J, Drab-Hudson D, Whisenhunt B, Srikameswaran S. Readiness to change dietary restriction predicts outcomes in the eating disorders. *Eating Disorders: The Journal of Treatment and Prevention*. 2004;12:219–24.

63. Geller J, Cockell SJ, Drab D. Assessing readiness for change in anorexia nervosa: The psychometric properties of the readiness and motivation interview. *Psychological Assessment*. 2001;13:189–98.
64. Bell L. What can we learn from consumer studies and qualitative research in the treatment of eating disorders. *Eating & Weight Disorders*. 2003;8:181–7.
65. Carr A, McNulty M. Eating Disorders. In: Carr A, McNulty M, editors. *The handbook of adult clinical psychology: an evidence-based practice approach*. East Sussex: Routledge; 2006. p. 724–65.
66. Vitousek K, Watson S. Enhancing motivation for change in treatment-resistant eating disorders. *Clinical Psychology Review*. 1998;18(4):391–420.
67. Miller W, Rollnick S. *Motivational interviewing: preparing people for change*. 2nd ed. New York: The Guilford Press; 2002.
68. Eisler I. The empirical and theoretical base for family therapy and multiple family day therapy for adolescent anorexia nervosa. *Journal of Family Therapy*. 2005;27:104–31.
69. Eisler I, Dare C, Hodes M, Russell G, Dodge E, Le Grange D. Family therapy for adolescent anorexia nervosa: the results of a controlled comparison of two family interventions. *Journal of child psychology and psychiatry*. 2000;41(6):727–36.
70. Lock J, Le Grange D, Stewart A, Moyer A, Bryson S, Booil J. Randomized Clinical Trial Comparing Family-Based Treatment with Adolescent-Focused Individual Therapy for Adolescents with Anorexia Nervosa. *Archives of General Psychiatry*. 2010;67(10):1025–32.
71. Loeb K, D. le G. Family-Based Treatment for Adolescent Eating Disorders: Current Status, New Applications and Future Directions. *International Journal of Child and Adolescent Health*. 2009;2(2):243–54.
72. Lock J, Fitzpatrick K. Advances in psychotherapy for children and adolescents with eating disorders. *American journal of psychotherapy*. 2009;63(4):287–303.

Chapter Three: Advanced Clinical Practice 1

Reflective Account

An unfortunate gap in service provision

Sinead O'Loughlin

***Submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology (DClinPsy)***

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Abstract

Reflective practice can be characterised as “learning through experience toward gaining new insights or changed perceptions of self or practice” (Johns, 2000, p 3). This reflective account focuses on my experience of Renal Services as a Trainee Clinical Psychologist. Starting from a point of having little knowledge of renal disease, I have developed an understanding chronic kidney disease, its treatment and associated psychological sequelae. Multiple sources contributed to the development of my understanding the psychological needs of renal patients including visiting a dialysis unit, individual therapeutic work with renal patients and a review of the literature in this area. I have come to recognise the significant gap in service provision for this patient group. This has both only brought feelings of sadness and frustration, but also provided motivation to act.

Chapter Four: Advanced Clinical Practice 2

Reflective Account

The role of psychology in aesthetic plastic surgery

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Abstract

Reflection has been defined “those intellectual and affective activities in which individuals engage to explore their experiences in order to lead to new understandings and appreciations”. This reflective account focuses on my experiences on placement in a Plastic Surgery and Burns Unit. In particular, it focuses on how I developed my understanding of the role of clinical psychologists in assessment of individuals referred via ‘The Adult Exceptional Aesthetic Referral Protocol’. Initially preconceptions about relative value of this role, compared to other roles performed by psychologists within the service, shifted as I learnt more about the prevalence of psychological issues amongst this population, risks associated with aesthetic surgery and the complexities of decision making. Multiple sources contributed to my learning including supervision, observation, therapeutic work and a review of the literature in this area.

Appendix 1.1 International Journal of Eating Disorders Authors Guidelines

International Journal of Eating Disorders



Edited By: Michael Strober

Impact Factor: 2.947

International Journal of Eating Disorders

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Please be sure to study the Instructions and Forms given at the site carefully, and then let the system guide you through the submission process. Online help is available to you at all times during the process. You are also able to exit/re-enter at any stage before finally "submitting" your work. All submissions are kept strictly confidential. If you have any questions, do not hesitate to contact us at support@scholarone.com.

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Manuscripts are received by the editorial office with the understanding that they represent original works, have not published previously, and are not under simultaneous review by another publication. If parts of the manuscripts have been presented at a scientific meeting, this should be indicated on the title page.

Manuscripts are evaluated by one to three members of the Editorial Board, or outside reviewers selected by the Editor. Accepted manuscripts become the permanent property of The International Journal of Eating Disorders and cannot be printed elsewhere without prior permission of the publisher.

Preparation of Manuscript

Number all pages of the manuscript except the figures (including title page and abstract) consecutively. Parts of the manuscripts should be arranged in the following sequence:

(1) Title page. (numbered 1) should include the full names, titles, and affiliations of all authors, and an abbreviated title (Running Head) that should not exceed 50 characters, counting letters, spacing, and punctuation. This Running Head should be typed in upper case letters centered at the bottom of the title page. Each page of the manuscript (excluding figures) should be identified by typing the first two or three words of the full title in the upper right-hand corner above the page number.

(2) Abstract. (150-word maximum) should be started on a separate page, numbered 2. Type the word "Abstract" in upper and lower case letters, centered at the top of page 2. Authors of articles submitted to the Journal involving research data or reviews of the literature must now include the following information in the form of a structured abstract, under the headings indicated. The abstract should be typed as a single paragraph on one page: **Objective:** briefly indicate the primary purpose of the article, or major question

addressed in the study. **Method:** indicate the sources of data, give brief overview of methodology, or, if review article, how the literature was searched and articles selected for discussion. For research based articles, this section should briefly note study design, how subjects were selected, and major outcome measures. **Results:** summarize the major or key findings. Discussion: indicate main clinical, theoretical, or research applications/implications. The *Journal* will continue to use unstructured abstracts for case reports.

(3) Text. Begin the text on page 3 and be sure to identify each page with the short title typed in the upper right-hand corner above the page number. Type the full title of the manuscript centered at the top, and then begin the text. The full title appears on page 3 only. Indent all paragraphs. While there is no maximum length for article submissions it is advisable that research be conveyed as concisely as possible.

(4) References. Begin on separate page, with the word "References" typed in upper and lower case letters, centered at the top of the page.

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(6) Footnotes. Start on separate page.

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(8) Figure captions. Start on separate page. Each figure caption should have a brief title that describes the entire figure without citing specific panels, followed by a description of each panel. Figure captions should be included in the submitted manuscript as a separate section. Be sure to explain abbreviations in figures even if they have already been explained in-text. Consider the tables and figures to be self-contained and independent of the text. They should be interpretable as stand-alone entities. Axes for figures must be labeled with appropriate units of measurement and description.

Manuscript Form and Presentation

All manuscripts are subject to copyediting, although it is the primary responsibility of the authors to proofread thoroughly and insure correct spelling and punctuation, completeness and accuracy of references, clarity of expression, thoughtful construction of sentences, and legible appearance prior to the manuscript's submission. Preferred spelling follows *Webster's New Collegiate Dictionary* or *Webster's Third New International Dictionary*. The manuscript should conform to accepted English usage and syntax.

Microsoft Word is the preferred format for the creation of your text and tables (one file with tables on separate pages at the end of your text). Refrain from complex formatting; the Publisher will style your manuscript according to the Journal design specifications. Do not use desktop publishing software such as Aldus PageMaker or Quark XPress.

Use headings to indicate the manuscript's general organization. Do not use a heading for the introduction. In general, manuscripts will contain one of several levels of headings. Centered upper case headings are reserved for Methods, Results, and Discussion sections of the manuscript. Subordinate headings (e.g., the Subjects or Procedure subsection of Methods) are typed flush left, underlined, in upper case and lower case letters. The text begins a new paragraph.

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All reference citations in the text should appear in the reference list. When there are less than seven authors, each must be listed in the citation. When seven or more authors, list the first six followed by et al. after the name of the sixth author. Representative examples are as follows:

Journal Article: 1. Endicott J, Spitzer RL. A diagnostic interview: The schedule for affective disorders and schizophrenia. Arch Gen Psychiatry 1978;35:837-844.

Book Chapter: 2. Fairburn CG, Cooper Z. The eating disorders examination (12th ed). In: Fairburn CG, Wilson GT, editors. Binge eating: nature, assessment, and treatment. New York: The Guilford Press, 1993, p. 317-331.

Book: 3. Tudorl. Learner-centeredness as language education. Cambridge: CambridgeUniversity Press; 1996.

Preparation of figures. To ensure the highest quality print production, your figures must be submitted in TIFF format according to the following minimum resolutions:

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- 300 dpi for halftones (black and white photographs)
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Graphs must show an appropriate grid scale. Each axis must be labeled with both the quantity measured and the unit of measurement. Color figures must be submitted in a CMYK colorspace. Do not submit files as RGB. All color figures will be reproduced in full color in the online edition of the journal at no cost to authors. Authors are requested to pay the cost of reproducing color figures in print. Authors are encouraged to submit color illustrations that highlight the text and convey essential scientific information. For best reproduction, bright, clear colors should be used.

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PROPOSED ADDITIONAL GUIDELINES FOR COPYEDITING OF MANUSCRIPTS FOR INTERNATIONAL JOURNAL OF EATING DISORDERS

The *Journal* Editor and Associate Editors propose additional guidelines for manuscript copyediting in order to enhance consistency in the organization of printed material, and to bring *IJED* style in line with other major scientific publications. The key elements follow.

1. Each structured abstract should consistently use these subheadings (at present, the headings vary somewhat from article to article): Objective, Method, Results, Discussion.
2. Many of our Authors use terms such as “anorexics” or “bulimics” as personal pronouns, referring to groups of individuals by their common diagnosis. Henceforth, these terms should be replaced with more neutral language, as for example: “individuals with anorexia nervosa”, “patients with bulimia nervosa”, or “participants with eating disorders”.
3. In the Methods section, the subheading “Subjects” should now be replaced with the subheading “Participants”, and this term should be used in place of “subjects” throughout the text.
4. Standard rules will continue to govern the use of capitalization in Headings and Subheadings. However, when a minor word in a Heading or Subheading actually has special or unique meaning, the rule should be overridden.
5. When referring to gender, “males and “females” should be used in cases where the study samples include both children (below age 18) and adults; when the participants comprise adults only, the terms “men” and “women” should be used. In articles that refer to children (i.e., below the age of 13), “boys” and “girls” should be used.
6. In articles that refer to genetic material, the names of genes should be spelled out in full the first time they appear in the text, after which an italicized abbreviation can be substituted.
7. The word “data” is plural so text should follow accordingly; for example, “The data show...the data are ... the data were”.

8. When an article references another article that appears in the very same issue of the *Journal*, (such occurrences are most likely in Special Issues), the citation will be updated by the copyeditor (i.e., volume number and pagination will be substituted for “in press”).
9. For information on how to present p values and other standard measurements see [IJED Statistical Formatting Requirements](#).
10. The Methods section should include a statement that the research was reviewed and approved by an institutional review board.

Appendix 1.2 Downs & Black checklist for the assessment of methodological quality

Paper	
Quality Assessor	
Date of Assessment	

Item	Reporting	Score
1	Is the hypothesis/aim/objectives of the study clearly described?	1 Yes 0 No
2	Are the main outcomes to be measured clearly described in the introduction or methods section? <i>If main outcomes are first mentioned in the results section, the question should be answered No</i>	1 Yes 0 No
3	Are the characteristics of the patients included in the study clearly described? <i>Inclusion/exclusion criteria</i>	1 Yes 0 No
4	Are the interventions of interest clearly described? <i>Treatments and comparators</i>	1 Yes 0 No
5	Are the distributions of principle confounders in each group of subjects to be compared clearly described? <i>A list of principle confounders is provided e.g. gender, age, socio-economic status</i>	1 Yes 0 No
6	Are the main findings of the study clearly described? <i>Simple outcome data could be reported for all major findings so that the reader can check the analyses and conclusions. Does not cover statistical tests.</i>	1 Yes 0 No
7	Does the study provide estimates of the random variability in the data for the main outcomes? <i>Normally distributed data – Std error, Std deviation or confidence intervals. Non-normally distributed data – inter-quartile range</i>	1 Yes 0 No
8	Have all important adverse events that may be a consequence of the intervention been reported? <i>Should be marked as Yes if study demonstrates that there was an attempt to measure adverse events.</i>	1 Yes 0 No
9	Have the characteristics of patients lost to follow-up been described? <i>Should be answered Yes where there were no losses to follow up or where losses to follow-up were so small that the findings would be unaffected by their inclusion (maximum 10 %). This should be answered No where a study does not report the number of patients lost to follow-up</i>	1 Yes 0 No
10	Have actual probability values been reported for the main outcomes except where the probability value is less than 0.001? <i>e.g. 0.035 rather than <0.05</i>	1 Yes 0 No
Reporting Items		Total Score /10

Item	External Validity	Score
11	<p>Were the subjects asked to participate in the study representative of the entire population from which they were recruited?</p> <p><i>The study must identify the source population for patients and describe how the patients were selected. Patients would be representative if they comprised the entire source population, an unselected sample of consecutive patients, or a random sample. Random sampling is only feasible where a list of all members of the relevant population exists. Where a study does not report the proportion of the source population from which the patients are derived, the question should be answered unable to determine.</i></p>	<p>1 Yes</p> <p>0 No</p> <p>0 unable to determine</p>
12	<p>Were those subjects who were prepared to participate representative of the entire population from which they were recruited?</p> <p><i>The proportion of those asked who agreed should be stated. Validation that the sample was representative would include demonstrating that the distribution of the main confounding factors was the same in the study sample and the source population.</i></p>	<p>1 Yes</p> <p>0 No</p> <p>0 unable to determine</p>
13	<p>Were the staff, places, and facilities where patients were treated representative of the treatment the majority of patients receive?</p> <p><i>For the question to be answered Yes the study should demonstrate that the intervention was representative of that in use in the source population. The question should be answered No if, for example, the specialist intervention was undertaken in a specialist centre unrepresentative of the hospitals most of the source population would attend.</i></p>	<p>1 Yes</p> <p>0 No</p> <p>0 unable to determine</p>
External validity Items		Total Score /3

Item	Internal Validity – Bias	Score
14	<p>Was an attempt made to blind the study subjects to the intervention they have received?</p>	<p>1 Yes</p> <p>0 No</p> <p>0 unable to determine</p>
15	<p>Was an attempt made to blind those measuring the main outcomes of the intervention?</p>	<p>1 Yes</p> <p>0 No</p> <p>0 unable to determine</p>
16	<p>If any of the results were based on “data dredging”, was this made clear?</p> <p><i>Any analyses that had not been planned at the outset of the study should be clearly indicated. If no retrospective unplanned subgroup analysis were reported, answer Yes.</i></p>	<p>1 Yes</p> <p>0 No</p> <p>0 unable to determine</p>
17	<p>In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?</p> <p><i>Where follow-up was the same for all participants or if different lengths of follow-up were adjusted for the answer should be Yes. If difference in follow-up were ignored answer No.</i></p>	<p>1 Yes</p> <p>0 No</p> <p>0 unable to determine</p>

18	<p>Were the statistical tests used to assess the main outcomes appropriate?</p> <p><i>The statistical techniques used must be appropriate to the data. For example non-parametric methods should be used for small sample sizes. Where little statistical analysis has been undertaken but where there is no evidence of bias the question should be answered Yes. If the distribution of the data (normal or not) is not described it must be assumed that tests used were appropriate and the question should be answered Yes.</i></p>	<p>1 Yes</p> <p>0 No</p> <p>0 unable to determine</p>
19	<p>Was compliance with the intervention/s reliable?</p> <p><i>Where there was non compliance with the allocated treatment or where there was contamination of one group, the question should be answered No.</i></p>	<p>1 Yes</p> <p>0 No</p> <p>0 unable to determine</p>
20	<p>Were the main outcome measures used accurate (valid and reliable)?</p> <p><i>For studies where the outcome measures are clearly described this question should be answered Yes. For studies which refer to other work or that demonstrate the outcome measures to be accurate, the question should be answered as Yes.</i></p>	<p>1 Yes</p> <p>0 No</p> <p>0 unable to determine</p>
Internal Validity Bias Items		Total Score /7

Item	Internal Validity – Confounding (selection bias)	Score
21	<p>Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?</p> <p><i>For example, patients for all comparison groups should be selected from the same hospital. The question should be answered unable to determine for cohort and case-control studies where there is no information concerning the source of patients included in the study.</i></p>	<p>1 Yes</p> <p>0 No</p> <p>0 unable to determine</p>
22	<p>Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?</p> <p><i>For a study which does not specify the time period over which patients were recruited, the question should be answered as unable to determine.</i></p>	<p>1 Yes</p> <p>0 No</p> <p>0 unable to determine</p>
23	<p>Were study subjects randomised to intervention groups?</p> <p><i>Studies which state that subjects were randomised should be answered Yes except where the method of randomisation should not ensure random allocation. For example alternative allocation would score No because it is predictable.</i></p>	<p>1 Yes</p> <p>0 No</p> <p>0 unable to determine</p>
24	<p>Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?</p> <p><i>All non-randomised studies should be answered No. If assignment was concealed from patients but not staff, it should be answered No.</i></p>	<p>1 Yes</p> <p>0 No</p> <p>0 unable to determine</p>
25	<p>Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?</p> <p><i>This question should be answered No for trials if: The main conclusions of the study were based on analyses of treatment rather than intention to treat; the distribution of known</i></p>	<p>1 Yes</p> <p>0 No</p> <p>0 unable to determine</p>

	<i>confounders in different treatment groups is not described; or the distribution of known confounders differed between treatment groups but was not taken into account in the analyses. In non-randomised studies if the effect of the main confounders was not investigated or confounding was demonstrated but not adjusted for in the final analyses the question should be answered as No.</i>	
26	Were losses of patients to follow-up taken into account? <i>If the number of patients lost to follow-up was not reported, the question should be answered as unable to determine. If the proportion of lost to follow-up was too small to affect the main findings, the question should be answered Yes.</i>	1 Yes 0 No 0 unable to determine
Internal Validity Confounding Items		Total Score /6

Item	Power	Score
27	Was the sample size in each group greater than 27 or was an adequate power calculation provided	1 Yes 0 No
Power		Total Score /1

All Quality Rating Items	Score /27
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Appendix 1.3 Full-text articles excluded from the current review

<i>Reasons for Exclusion</i>	<i>Reference</i>
Qualitative studies	<p>Macdonald P, Murray J, Goddard E, Treasure J. Carer's experience and perceived effects of a skills based training programme for families of people with eating disorders: a qualitative study. <i>European Eating Disorder Review</i>. 2011;19(6):475–86.</p> <p>Zucker NL, Ferriter C, Best S, Brantley A. Group parent training: a novel approach for the treatment of eating disorders. <i>Eating Disorders</i>. 2005;13(4):391–405.</p> <p>Goddard E, Macdonald P, Treasure J. An examination of the impact of the Maudsley Collaborative Care skills training workshops on patients with anorexia nervosa: A qualitative study. <i>European Eating Disorder Review</i>. 2010;19:150–61.</p>
No psychosocial or QOL outcome measures	<p>Cairns JC, Styles LD, Leichner P. Evaluation of meal support training for parents and caregivers using a video and a manual. <i>Journal of the Canadian Academy of Child and Adolescent Psychiatry</i>. 2007 Nov;16(4):164–6.</p> <p>Holtkamp K, Herpertz-Dahlmann B, Vloet T, Hagenah U. Group psychoeducation for parents of adolescents with eating disorders: the Aachen program. <i>Eating Disorders</i>. 2005;13(4):381–90.</p> <p>Nicholls D, Magagna J. A Group for the Parents of Children with Eating Disorders. <i>Clinical Child Psychology and Psychiatry</i>. 1997;2(4):565–78.</p> <p>Lewis HL, MacGuire MP. Review of a group for parents of anorexics. <i>Journal of Psychiatric Research</i>. 1985;19(2-3):453–8.</p> <p>Rose J, Garfinkel P. A parents' group in the management of anorexia nervosa. <i>Canadian Journal of Psychiatry</i>. 1980;25(3):228–33.</p> <p>Zucker N, Marcus M, Bulik C. A group parent-training program: a novel approach for eating disorder management. <i>Eating & Weight Disorders</i>. 2006;11(2):78–82.</p>
Not a carers intervention	<p>Geist R, Heinmaa M, Stephens D, Davis R, Katzman D. Comparison of family therapy and family group psychoeducation in adolescents with anorexia nervosa. <i>Canadian Journal of Psychiatry</i>. 2000;45(2):173-8.</p>
Not intervention studies	<p>Pasold TL, Boateng B, Portilla MG. The use of a parent support group in the outpatient treatment of children and adolescents with eating disorders. <i>Eating Disorders</i>. 2010;18(4):318–32.</p> <p>Treasure J, Whitaker W, Todd G, Whitney J. A description of multiple family workshops for carers of people with anorexia nervosa. <i>European Eating Disorder Review</i>. 2012;20(1):e17–22.</p>
Not a skills based or educational intervention	<p>Rhodes P, Baillee A, Brown J, Madden S. Can parent-to-parent consultation improve the effectiveness of the Maudsley model of family-based treatment for anorexia nervosa? A randomized control trial. <i>Journal of Family Therapy</i>. 2008;30(1):96–108.</p>

Appendix 1.4 Full description of interventions from included studies

Intervention type		Studies	Description
Self-help interventions	DVD and Manual	Goddard et al. ³⁶	All carers received a book and 5 DVDs. Materials include many behaviour change strategies including: identification of barriers to change, graded tasks, behavioural goals and stress management skills. Carers in the guided self-help condition received 3 telephone coaching sessions of 40 min. (plus an introductory phone call).
		Sepulveda et al. ⁴¹	Carers were given a manual and 5 DVDs. Key content included: Identifying interpersonal interactions that may play a role in maintaining illness, establishing supported eating habits, 'stages of change model', MI techniques and functional analysis of problematic behaviours. Coaching sessions lasted 30 min. (3 sessions)
	Web-Based	Grover et al. ³⁷	Carers in the intervention condition were able to access 8 web-based modules. These provided information, promoted self-monitoring and taught skills to understand & manage AN symptoms. Based on CBT and MI. Guidance of up to 20 min. per week while completing modules. Carers in the control condition had access to support from the charity Beat.
	Workbook	Grover et al. ³⁸	Workbook intervention for AN carers with clinician support: 9 interactive workbooks and weekly support of up to 20 min. per week while completing workbooks (e-mail or telephone). Key content included: information regarding ED, CBT approach, 'stages of change' model, principles of MI & helping carers attend to their own needs.
Workshop or Group Interventions	Workshop	Sepulveda et al. ³⁹	6 workshops over a 3 month period. The workshops provided education about factors that maintain eating disorders, including EE, and taught basic behavioural change skills with the aim of changing both the carers own behaviour and that of the service user.
	Workshop	Sepulveda et al. ⁴⁰	6 workshops over a 3 month period, teaching practical skills based on elements of CBT and MI. 1 follow-up workshop 3 month post-intervention.
	Workshop	Uehara et al. ⁴²	5 workshops over a 5 month period. Provided education about ED and support to enhance family functioning. Used solution focused problem-solving, and externalisation skills.
	Group	Gísladóttir & Svavarsdóttir ³⁵	4 group sessions, held on a weekly basis. Groups provided education about ED and the role of relatives, validating emotional responses, supporting development of constructive beliefs and helping carers externalise the ED from the person.
Eating Disorders (ED); Anorexia Nervosa (AN); Cognitive Behavioural Therapy (CBT); Motivational Interviewing (MI); Expressed Emotion (EE)			

Appendix 1.5 Outcome measures used in included studies

Domain	Assessment Tool	Brief description
	Studies used by	
Carer distress	Hospital Anxiety and Depression Scale (HADS) ⁴⁸	14-item self-report measure assessing symptoms of anxiety and depression over the previous week using a 4-point Likert scale. The scale is divided into an anxiety subscale and a depression subscale. Total subscale scores range from 0 to 21. Scores between 0 and 7 are within the normal range; scores of 8 to 10 indicate difficulties, and scores greater than 11 indicate “caseness”.
	Grover et al. ³⁷ Grover et al. ³⁸ Goddard et al. ³⁶ Sepulveda et al. ⁴¹	
	The General Health Questionnaire (GHQ) ⁴⁹	12-item self-report measure assessing general well-being over the past few weeks using a 4 point Likert scale. Total scores range from 0 to 36, where higher scores indicate greater psychological distress.
	Goddard et al. ³⁶ Sepulveda et al. ³⁹ Sepulveda et al. ⁴⁰ Sepulveda et al. ⁴¹	
	Profile of Mood States – Japanese Version II (POMS) ⁵⁰	65-item self-report measure assessing the mental and psychological status over the past week using a 5-point Likert scale. It consists of six subscales (anxiety, depression, anger, vigour, fatigue, and confusion). Total score ranges from 0-200.
	Uehara et al. ⁴²	
Experience of Caregiving	Experience of Care Giving Inventory (ECI) ⁵¹	66-item self-report measure that assesses different aspects of the care giving experience. Items explore positive (14 items) and negative (52 items) aspects of caring using a 5-point Likert scale. On the negative subscale higher scores reflect more negative appraisals. While on the positive subscale higher scores mean more positive appraisal.
	Goddard et al. ³⁶ Grover et al. ³⁷ Grover et al. ³⁸ Sepulveda et al. ³⁹ Sepulveda et al. ⁴⁰ Sepulveda et al. ⁴¹	
	The Eating Disorders Symptoms Impact Scale (EDSIS) ⁵²	24-item scale that measures caregiving burden related to specific symptoms of the eating disorder using a 5-point Likert scale. It has four subscales: impact of starvation, guilt, social isolation and dysregulated behaviours. Total scores range from 0 to 96, where higher scores indicate more negative appraisal.
	Goddard et al. ³⁶ Grover et al. ³⁷ Grover et al. ³⁸ Sepulveda et al. ⁴⁰	
	The Revised Scale for Caregiving Self-Efficacy (CSE) ⁵³	15-item self-report measure that assesses caregiving self-efficacy across 3 domains: Obtaining Respite, Responding to Disruptive Patient Behaviours, and Controlling Upsetting Thoughts. Scores are marked on a Likert scale ranging from 1 to 100, where 0 represents 0% confidence and 100 represents 100% confidence.
	Goddard et al. ³⁶	
Expressed Emotion	Five Minute Speech Sample (FMSS) ⁵⁴	The FMSS is a brief method for assessing Expressed Emotion (EE) based on a 5-minute interview with the carer about their relationship with their loved one. The tone and content of the interview is rated for levels of EE. Expression of criticism, a negative relationship or a negative initial statement will result in rating of high-EE based on criticism. Emotional displays during the interview, reports of self-sacrifice or overprotection will result in a rating of high-EE based on emotional over-involvement (EOI). A rating of EOI is also given if any two of the three following apply: excessive irrelevant details, statements of strong love/willingness to do anything or at least five positive remarks.
	Grover et al. ³⁸ Sepulveda et al. ³⁹ Uehara et al. ⁴²	

	Level of Expressed Emotion Scale (LEE) ⁵⁵	60-item self-report measure assessing expressed emotion across four dimensions: intrusiveness, emotional response, understanding, and tolerance/expectations. Total scores fall between 0 and 60. High EE is identified as any score which falls above the median score for the group.
	Gísladóttir & Svavarsdóttir ³⁵ Grover et al. ³⁷ Grover et al. ³⁸	
	The Family Questionnaire (FQ) ⁵⁶	20-item self-report measure assessing emotional response using a 4-point Likert scale. 10 items address criticism and 10 for emotional over-involvement. A higher score indicates higher EE.
	Gísladóttir & Svavarsdóttir ³⁵ Goddard et al. ³⁶ Sepulveda et al. ⁴¹	
Family functioning	Family Adaptability and Cohesion Evaluation Scales - Japanese version (FACES-KG) ⁵⁷	20-item self-report measure of family functioning. The measure contains two scales: cohesion (enmeshed/disengaged) and adaptability (rigid/chaotic). Uehara et al. ⁴² employed the following scoring criteria, “a balanced family function score was considered to lie between both 33 to 43 points of cohesion and 40 to 52 points of adaptability”.
	Uehara et al. ⁴²	
	Accommodation & Enabling Scale for Eating Disorders ⁵⁸ (AESED)	33-item self-report measure assessing behaviours that may serve to accommodate the eating disorder using a 5-point Likert scale. A higher score is associated with higher family accommodation to eating disorder symptoms.
	Goddard et al. ³⁶ Grover et al. ³⁷	
Service user outcomes	Global Assessment of Functioning scale (GAF) ⁶⁰	A clinician rated measure of social, occupational and psychological functioning of adults. Total scores range from 1 to 100, where 100 is the least impaired.
	Uehara et al. ⁴²	
	Global Eating Disorders Functioning (GEDF)	Adapted for carers from the Global Assessment of Functioning scale. A self-report measure in which carers assess the social, occupational and psychological functioning of their loved one. Total scores range from 1 to 100, where 100 is the least impaired.
	Goddard et al. ³⁶	
	Anorectic behaviour observation scale questionnaire (ABOS) ⁶¹	30-item self-report measure assessing the specific symptoms of eating disorders. 3 answer options (yes, no, don't know). The measure contains three subscales: (1) eating behaviour, concern with weight and food, and denial of the problem; (2) bulimic-like behaviour; and (3) hyperactivity. Higher scores indicate a greater presence of symptoms.
	Gísladóttir & Svavarsdóttir ³⁵ Uehara et al. ⁴²	
	Eating Disorder Evaluation Scales (EDES) ⁵⁹	A clinical judgment instrument for assessing severity of eating disorders. It contains 15 items, with a maximum score of 90 points.
	Uehara et al. ⁴²	
Problem Solving	Eating Behaviours (EatBeh)	In this self-report measure carers are asked to identify eating disorder behaviours in their loved one e.g. severely underweight, restricting food intake, excessive exercising, vomiting, missing menstrual periods, binge eating. The total number of items endorsed is summed, with higher scores indicating a greater presence of symptoms
	Goddard et al. ³⁶	
	Social Problem Solving Inventory - Revised (SPSI-R) ⁶²	
	Grover et al. ³⁸	52-item self-report measure that assesses strengths and weaknesses in an individual's problem-solving abilities across five different dimensions: positive problem orientation, negative problem orientation, rational problem solving, impulsivity/carelessness, and avoidance. Raw scores are converted to standardised scores which can be compared against normative data for different age groups.

Appendix 2.1 West of Scotland Research Ethics Service Approval

WoSRES
West of Scotland Research Ethics Service



West of Scotland REC 2

Ground Floor, Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT
www.nhsggc.org.uk

Dr Kenneth Mullen
Lecturer in Medical Sociology
University of Glasgow
Academic Unit for Mental Health & Well Being
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Date 14 November 2011
Direct line 0141-211-1722
Fax 0141-211-1847
e-mail evelyn.jackson@ggc.scot.nhs.uk

Dear Dr Mullen

Study title:	Transition from child and adolescent to adult services in eating disorders - A study of user and carer perspectives
REC reference:	11/WS/0050

Thank you for your letter of 3 November 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

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

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

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

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

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

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www.nhsggc.org.uk

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

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

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

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

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

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Advertisement	2	29 August 2011
Interview Schedules/Topic Guides	2-Service Users	26 August 2011
Investigator CV		02 September 2011
Letter of invitation to participant	1	29 July 2011
Other: Opt In Form	1	15 July 2011
Other: Letter to Clinician	1	31 August 2011
Other: Letter to Clinician and Clinical Information Form	2	26 August 2011
Other: Semi Structured Interview Schedule - Carers	2	26 August 2011
Other: CV Student - Sinead O'Loughlin		26 August 2011
Participant Consent Form	3	29 August 2011
Participant Information Sheet	3	29 August 2011
Participant Information Sheet: Carer	-	02 November 2011
Participant Information Sheet: Service User	-	02 November 2011
Protocol	6	02 September 2011
REC application	-	31 August 2011
Response to Request for Further Information	-	03 November 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

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

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

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

Feedback

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

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

11/WS/0050	Please quote this number on all correspondence
------------	------------------------------------------------

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

Yours sincerely



 Dr Sue Langridge
Chair

Enclosures: List of names and professions of members who were present at the meeting
and those who submitted written comments
"After ethical review – guidance for researchers"

Copy to: ✓ Miss Sinead O'Loughlin, Gartnavel Royal Hospital
Dr Erica Packard, R&D Office, Tennent Building, Western Infirmary

Appendix 2.2 West of Scotland Research Ethics - Minor Amendment

WoSRES

West of Scotland Research Ethics Service

COPY FOR YOUR NHS
INFORMATION
Greater Glasgow
and Clyde

West of Scotland REC 2

Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow
G11 6NT

Dr Kenneth Mullen
Lecturer in Medical Sociology
University of Glasgow
Academic Unit for Mental Health
& Well Being
Gartnavel Royal Hospital
1055 Great Western Road, Glasgow
G12 0XH

Date 12 December 2011

Direct line 0141 211 2482
Fax 0141 211 1847
E-mail rose.gallacher@ggc.scot.nhs.uk

Dear Dr Mullen

Study title: Transition from child and adolescent to adult
services in eating disorders - A study of user and
carer perspectives
REC reference: 11/WS/0050
Amendment number: AM01
Amendment date: 06 December 2011

Thank you for your letter of 06 December 2011, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

Document	Version	Date
Advertisement	3	06 December 2011
Notification of a Minor Amendment	AM01	06 December 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

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11/WS/0050:

Please quote this number on all correspondence

Yours sincerely

R Gallacher

Mrs Rose Gallacher
Committee Assistant Co-ordinator

Copy to: *Miss O'Loughlin Sinead*
Erica Packard, Research and Development Central Office

Appendix 2.3 NHS Lanarkshire Research and Development Approval



Dr Kenneth Mullen
Post Lecturer in Medical Sociology
University of Glasgow
Academic Unit for Mental Health &
Well Being
Gartnavel Royal Hospital
1055 Great Western Road, Glasgow
G12 0XH

R&D Department
Corporate Services Building
Monklands Hospital
Monkscourt Avenue
AIRDRIE
ML6 0JS

Date 18 November 2011
Enquiries to Margaret Stewart,
R&D Facilitator
Direct Line 01236 712445
Email margaret.stewart@lanarkshire.scot.nhs.uk

Dear Dr Mullen,

Miss O'Loughlin

PROJECT TITLE: Transition from child and adolescent to adult services in eating disorders - A qualitative study of user and carer perspectives

R&D ID NUMBER: L11088

NRS ID NUMBER : NRS11/MH52

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS Lanarkshire as detailed below:

NAME	TITLE	ROLE	NHSL SITE TO WHICH APPROVAL APPLIES
Miss Sinead O'Loughlin	Trainee Clinical Psychologist,	PI (Greater Glasgow & Clyde)	Eating Disorders Specialist Service Psychological Therapy Service CAMHS

For the study to be carried out you are subject to the conditions outlined overleaf:

Cont/...

Conditions

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and the Data Protection Act 1998.
- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: <http://www.show.scot.nhs.uk/cso/> or the Research & Development Intranet site: <http://firstport/sites/randd/default.aspx>).
- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research & Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.
- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.
- You must contact the R&D Department if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.
- You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire.
- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.
- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.
- If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for an SCRO check and occupational health assessment. If this is the case then please contact the R&D Department to make arrangements for this to be undertaken and an honorary contract issued.

I trust these conditions are acceptable to you.

Cont/...

Yours sincerely,



Raymond Hamill
Research & Development Manager

cc.

NAME	TITLE	CONTACT ADDRESS	ROLE
Miss Sinead O'Loughlin	Trainee Clinical Psychologist	Gartnavel Royal Hospital, NHS Greater Glasgow & Clyde	Principal Investigator / Local Collaborator
As above (Sinead O'Loughlin)			Sponsor Contact
Dr Christine Watson	Clinical Psychologist	Tier 3 Eating Disorder Specialist Service (TESS), Buchanan Centre, Coatbridge	Local Named Contact

c.c – (email)

nhsgrsrcc@nhs.net

Appendix 2.4 NHS Greater Glasgow & Clyde Research and Development Approval



Coordinator/Administrator: Dr Erica Packard/Mrs Elaine O'Neill
Telephone Number: 0141 211 6208
E-Mail: erica.packard@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

R&D Management Office
Western Infirmary
Tennent Institute
1st Floor 38 Church Street
Glasgow, G11 6NT,

18 November 2011

Miss Sinead O'Loughlin
Trainee Clinical Psychologist
Mental Health & Wellbeing
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH

NHS GG&C Board Approval

Dear Miss O'Loughlin,

Study Title:	Transition from child and adolescent to adult services in eating disorders - A qualitative study of user and carer perspectives.
Principal Investigator:	Miss Sinead O'Loughlin
GG&C HB site	NHS GG&C Community
Sponsor	NHS Greater Glasgow and Clyde
R&D reference:	GN11CP317
REC reference:	11/WS/0050
Protocol no:	V6; 06/09/11
(including version and date)	

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
 - a. During the life span of the study GGHB requires the following information relating to this site
 - i. Notification of any potential serious breaches.
 - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

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www.nhsggc.org.uk

Page 1 of 2

R&D Approval Letter GN11CP317

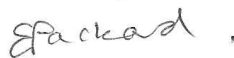
2. **For all studies** the following information is required during their lifespan.
- a. Recruitment Numbers on a quarterly basis
 - b. Any change of staff named on the original SSI form
 - c. Any amendments – Substantial or Non Substantial
 - d. Notification of Trial/study end including final recruitment figures
 - e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,



Dr Erica Packard
Research Co-ordinator

Cc: NRSPCC

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Page 2 of 2

R&D Approval Letter GN11CP317

Appendix 2.5 NHS Dumfries & Galloway Research and Development Approval

Research and Development Support Unit
Ground Floor
Dumfries and Galloway Royal Infirmary
Bankend Road
Dumfries
DG1 4AP



Dr Kenneth Mullen
Section of Psychological Medicine
Gartnavel Royal Hospital
1055 Great Western Road, Glasgow.
1055 Great Western Road
Glasgow
G12 0XH

Date: 18th November 2011

Our ref: 11/DGY/042

Study title: A qualitative study of transitional care in eating disorders

Dear Dr Mullen

Thank you for sending me details of your study with a request for management approval. I can confirm that the study review team has reviewed the documentation and on this basis I am pleased to inform you that your study has management approval for commencement within NHS Dumfries and Galloway.

It is a condition of this approval that everyone involved in this study abides by the guidelines/protocols laid down by this Health Board in respect of confidentiality and Research Governance. It is your responsibility to ensure you are familiar with these; please do not hesitate to seek advice if you are unsure. (Copies of Research Governance Framework document available via the website www.sehd.scot.nhs.uk/cso and then use the publications link).

We also note that it is the sponsor's responsibility to ensure that appropriate training is in place for all local investigators. It is important that all research must be carried out in compliance with the Research Governance Framework for Health and Community Care and the new EU Clinical Trials Directive (for clinical trials involving investigational medicinal products).

As part of the Health Board's responsibilities under Research Governance a sample of studies will be monitored, and it is therefore important that all records in connection with the study are kept up to date and available for review. We are also required to inform you that details of your study will be entered onto our R&D database. As custodian of the information collated during this research project, you are responsible for ensuring the security of all personal information collected, in line with NHS Scotland IT Security Policies, until the destruction of this data.

Research and Development Support Unit
Ground Floor
Dumfries and Galloway Royal Infirmary
Bankend Road
Dumfries
DG1 4AP




If your study is adopted by UKCRN into a portfolio then please advise this department of recruitment figures by adding accrual data to that database on a monthly basis.

Please notify the R&D office immediately you become aware of any serious adverse events associated with this research.

You must contact the R&D Department if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary. I understand that performance of this study will not infringe on NHS Dumfries and Galloway's ability to deliver our usual level of service.

May I take this opportunity to wish you every success with your project. Please do not hesitate to seek help and advice from the R&D Support Unit (ext 33164 and 33165) if there is anything which you feel you would like assistance with. I look forward to hearing about your work as it progresses and would appreciate a short annual report and a final report when the study is complete.

Yours Sincerely,

 J.R. Lawrence
R&D Director

CC NRS

Appendix 2.6 NHS Ayrshire & Arran Research and Development Approval

Healthcare Quality, Governance and Standards Unit
Research, Development & Evaluation Office
58 Lister Street
Crosshouse Hospital
Kilmarnock
KA2 0BB



Miss Sinead O'Loughlin
Trainee Clinical Psychologist
NHS Greater Glasgow & Clyde
Academic Unit for Mental Health and
Well Being
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Tel: (01563) 825856
Fax: (01563) 825806

Date: 18 November 2011
Your Ref:
Our Ref: CAW/KLB/NM R&D 2011AA066

Enquiries to: Karen Bell
Extension: 25850
Direct Line: 01563 825850
Email: Karen.bell@aaaht.scot.nhs.uk

Dear Miss O'Loughlin

Transition from child and adolescent to adult services in eating disorders - A study of user and carer perspectives

I confirm that NHS Ayrshire and Arran have reviewed the undernoted documents and grant R&D Management approval for the above study.

Approved documents:

Document	Version	Date
Generic SSI Form	Version 3.3	12/09/11 signed
R&D Form	Version 3.3	13/09/11 signed
Interview Schedule for Carers	Version 2.0	26/08/11
Interview Schedule for Service Users	Version 2.0	26/08/11
Invitation Letter	Version 1.0	29/07/11
Letter to Clinician & Clinical Information Form	Version 2.0	26/08/11
Service User Information Sheet	Version 4.0	02/11/11
Carer Information Sheet	Version 4.0	02/11/11
Participant Information Sheet	Version 3.0	29/08/11
Participant Opt-In Form	Version 1.0	15/07/11
Participant Consent form	Version 3.0	29/08/11
SEDIG Advertisement	Version 2.0	29/08/11

The terms of approval state that the investigator authorised to undertake this study is: -

- Miss Sinead O'Loughlin, NHS Greater Glasgow & Clyde

With no additional investigators.

PLEASE NOTE: Our Information Governance department asked us to highlight that if possible no personal information is held on a University laptop. If this is not possible however they request that the researcher keeps the amount of personal details to an absolute minimum, that it is only held on the laptop for the least time possible and that if during transit and storage that it is kept secure at all times i.e. out of site and locked away when not in use.

The sponsors for this study are NHS Greater Glasgow and Clyde.

This approval letter is valid until 18 January 2013.

R&D 2011AA066
Transition from child and adolescent to adult services in eating disorders - A study of user and carer perspectives

Regular reports of the study require to be submitted. Your first report should be submitted to Dr K Bell, Research & Development Manager in 12 months time and subsequently at yearly intervals until the work is completed.

Please note that as a requirement of this type of study your name, designation, work address, work telephone number, work e-mail address, work related qualifications and whole time equivalent will be held on the Scottish National Research Database so that NHS R&D staff in Scotland can access this information for purposes related to project management and report monitoring.

In addition approval is granted subject to the following conditions: -

- All research activity must comply with the standards detailed in the Research Governance Framework for Health and Community Care www.cso.scot.nhs.uk/publications/ResGov/Framework/RGFEEdTwo.pdf and appropriate statutory legislation. It is your responsibility to ensure that you are familiar with these, however please do not hesitate to seek further advice if you are unsure.
- You are required to comply with Good Clinical Practice (ICH-GCP guidelines may be found at www.ich.org/LOB/media/MEDIA482.pdf), Ethics Guidelines, Health & Safety Act 1999 and Data Protection Act 1998.
- If any amendments are to be made to the study protocol and or the Research Team the Researcher must seek Ethical and Management Approval for the changes before they can be implemented.
- The Researcher and NHS Ayrshire and Arran must permit and assist with any monitoring, auditing or inspection of the project by the relevant authorities.
- The NHS Ayrshire and Arran Complaints Department should be informed if any complaints arise regarding the project and the R&D Department must be copied into this correspondence.
- The outcome and lessons learnt from complaints must be communicated to funders, sponsors and other partners associated with the project.
- As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collated in line with NHS Scotland IT Security Policies, until the destruction of these data. Under no circumstances should personal data be stored on any unencrypted removable media e.g. laptop, USB or mobile device (for further information and guidance please contact the Information Governance Team based at Ailsa Hospital 01292 513693 or 513694).

If I can be of any further assistance please do not hesitate to contact me. On behalf of the department, I wish you every success with the project.

Yours sincerely



Professor Craig A White
Assistant Director (Healthcare Quality, Governance and Standards)

c.c. Erica Packard, NHS Greater Glasgow and Clyde (sponsor contact)
Dr Kenneth Mullen, Academic Supervisor, University of Glasgow
Pamela McColm, Consultant Clinical Psychologist, NHS A&A
Dr Christine Watson, Academic Supervisor
Lesley Douglas, Finance, Ailsa Hospital
Information Governance, Ailsa Hospital
NRS Coordinating Centre, Aberdeen

Appendix 2.7 Sample Participant Information Sheet

Mental Health and Wellbeing
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH



<p>Service User Information Sheet (02/11/2011)</p>

Study Title: Transition from child and adolescent to adult services in eating disorders - A study of service user and carer perspectives

You are being invited to take part in a research study. Before you decide if you would like to take part, it is important to understand why the research is being carried out and what it will involve. Please take the time to read the following information. Ask us if there is anything that is not clear or if you would like more information.

Who is conducting the research?

The research is being carried out by Sinead O'Loughlin and Dr Kenneth Mullen from Glasgow University, alongside Dr Christine Watson from the Eating Disorders Specialist Service in NHS Lanarkshire.

What is the purpose of this study?

We want to know about the experiences of young people with eating disorders and their carers, during the move from child and adolescent to adult services. We would like to find out how this transition was for you and aim to explore topics such as:

- How you feel about the transition
- What the good or difficult parts of this were
- How your well-being has been affected by the transition
- Whether there have been any changes in the treatment you receive

Learning about your experiences will help us to understand how services can support other young people with eating disorders and their families during the transition between services. We are hoping that with this information we will be able to make changes to improve and develop services.

Why have I been invited to take part?

We are inviting service users and carers, who have moved from child and adolescent to adult services in the past five years, whilst receiving treatment for an eating disorder, to take part in this study.

Do I have to take part?

No, you do not have to take part in this study. It is up to you to decide whether or not to take part. Even if you decide that you will take part, you are free to withdraw at any time and without giving a reason. A decision to stop, or a decision not to take part, will not affect the care that you receive or any future treatment.

What do I do if I want to take part?

If you are interested in taking part, please fill in the opt-in form and return it in the envelope provided. Alternatively, you can get in touch with the research team using the contact details provided below.

What will happen if I take part?

Once we receive your opt-in form I, Sinead O'Loughlin, will get in touch with you. I will answer any questions you might have and explain what will be involved in the interview process. I may ask your permission to contact your key-worker or psychiatrist, to confirm diagnosis and make sure that taking part will not interfere with any treatment you may be receiving. Please be assured that, if you decided to take part in the study, any information you share will remain confidential and will not be shared with your clinician.

If you are happy to go ahead with the interview we can arrange a suitable time to meet. We will meet on one occasion for about one hour. This meeting will take place at the base of your NHS treatment provider. If travelling to this base is difficult for you it may be possible to meet at a local NHS site, such as your GP surgery, or to conduct the interview by phone.

At the start of our meeting I will talk through the consent form with you and answer any final questions you may have. The consent form is a way of making sure you know what you have agreed to and you will be asked to sign this if you are happy for the meeting to proceed. I will then ask about your experience of the transition from child and adolescent to adult services. There are no right or wrong answers. It is your personal experience I would like to hear.

The meeting will be voice recorded to ensure all important aspects of your experience are captured. You are free to stop the recording at any time.

What are the possible benefits of taking part?

As someone who has undergone a transition from child and adolescent to adult services during treatment, taking part in this study will provide you with the opportunity to discuss your experiences. The insights that you can provide will help us to:

- Identify factors that are helpful or unhelpful during transition
- Recognise gaps in services
- Make recommendations about how services can make the process of transition a smooth and supportive experience for other young people with eating disorders and their families.

What is the down side to taking part?

Some people may feel uncomfortable discussing their experiences. You can take a break or end the interview at any point if you do not want to continue.

Will my taking part be kept confidential?

Yes. Your personal information will be kept confidential and known only to the researcher team. I will type up each interview. A sample of voice recordings and interview transcripts will be reviewed by Dr Kenneth Mullen and Dr Christine Watson to ensure accuracy. Any details which could potentially identify you, such as names or locations, will be removed or changed. Interview transcripts will be stored on a secure computer and voice recordings will be deleted at the end of the study. I will ask your permission to use quotations from the interview in reports about the study.

If you share information that makes me concerned for your safety or the safety of other people, I may be required to tell others involved in your care (e.g. your key-worker or psychiatrist). I will always notify you beforehand if I am going to do this, and explain why.

What will happen to the results of the study?

I will provide you with a summary of the results of the study. The final results and conclusions of the study will be published in a scientific journal and will form part of my qualification as a Clinical Psychologist.

Who is organising and funding the research?

The University of Glasgow and NHS Greater Glasgow & Clyde will organise and fund the research.

Who has reviewed the study?

This study has been reviewed by Mental Health and Wellbeing at Glasgow University to ensure that it meets important standards for scientific conduct and it has been reviewed by the NHS West of Scotland Ethic Committee to ensure it meets important standards of ethical practice.

Who do I contact if I want more information?

You may contact any of the researchers involved in this study if you have any questions or want further information. An independent contact person is also available for this study. The independent contact is Dr. Sarah Wilson, who is an experienced researcher based at Mental Health and Wellbeing. She has no direct involvement in this study and can provide impartial advice about the research.

<i>Role</i>	<i>Name</i>	<i>E-mail address</i>	<i>Phone Number</i>
Primary Researcher	Sinead O'Loughlin	s.o'loughlin.1@research.gla.ac.uk	To be added
Academic Supervisor	Dr Kenneth Mullen	Kenneth.Mullen@glasgow.ac.uk	0141 2113932
NHS Supervisor	Dr Christine Watson	Christine.Watson2@lanarkshire.scot.nhs.uk	01236 703402
Independent Contact	Dr Sarah Wilson	Sarah.Wilson@glasgow.ac.uk	141 211 3921

Thank you for reading this information

Appendix 2.8 Participant Opt In Form

Mental Health and Wellbeing
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH



Opt in Form
Version 1 – (15/07/11)

Title of Study: Transition from child and adolescent to adult services in eating disorders - A study of service user and carer perspectives

Thank you for considering participation in the above study. Please fill complete the below information and return it in the provided stamped addressed envelope. Alternatively you can contact me directly at the below number or e-mail address.

Name of Primary researcher: Sinead O'Loughlin

Contact number: (Number will be added here)

E-mail Address: s.o'loughlin.1@research.gla.ac.uk

Name: _____

Address: _____

Telephone number: _____

E-mail address: _____

Please tick relevant boxes

I am a service user ☐

I am a carer ☐

The best way to contact me is by:

Letter ☐ Telephone ☐ E-mail ☐

Appendix 2.9 Participant Consent Form

Participant Consent Form

Version 3 (29/08/2011)



Title of Study: Transition from child and adolescent to adult services in eating disorders - A study of service user and carer perspectives

Name of primary researcher: Sinead O'Loughlin

Contact Address: Mental Health and Well Being
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow, G12 0XH

Please initial each box:

I confirm that I have read and understand the participant information sheet for the above study and have had the opportunity to ask any questions.

☐

I understand that my participation in the study is voluntary and that I am free to withdraw from the study at any time, without giving any reason, and without my medical care or legal rights being affected.

☐

I give consent for the primary researcher to obtain basic information pertaining to my diagnosis from my clinician. This will include diagnoses, duration of illness, severity of illness and age at transition.

☐

I understand that if I disclose information that leads to concerns about safety, the researcher may be required to inform others involved in my care (e.g key worker).

☐

I understand that my interview will be audio-recorded, solely for the purposes of the research study described in the participant information sheet.

☐

I understand that all names, references to places and anything that could identify me will be anonymised or removed from my interview transcript.

☐

I give consent for the researcher to use extracts from my interview transcripts in reports about the research.

☐

I understand that this research may be published in a scientific journal and I give consent for the researcher to use extracts from my interview transcripts for this purpose.

☐

I agree to take part in the above study.

☐

Name of Participant

Date

Signature

Name of researcher taking consent

Date

Signature

**Letter to Clinician &
Clinical Information Form Version 2
(26/08/2011)**



Mental Health and Well Being
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Contact number: Number will be added here
E-mail Address: s.o'loughlin.1@research.gla.ac.uk

Transition from child and adolescent to adult services in eating disorders - A study of service user and carer perspectives

Dear (Name of clinician),

Many thanks for your support of the above research project. You will be aware that your patient, (service user name), has recently participated in this study. (Service user name) has consented for you to provide information pertaining to his/her diagnosis for the purposes of this research. I enclose a clinical information form detailing the information we request. I would appreciate if you could complete this form and return it to me, in the envelope provided, at your earliest convenience.

If you have any queries regarding this please do not hesitate to contact me.

Yours sincerely

Sinead O'Loughlin

Trainee Clinical Psychologist

Clinical Information Form

Service User Identifier:

Unique code number

Diagnoses:

Age of onset of eating disorder:

Severity of eating disorder:

Age at transition from CAMHS to adult services:

Length of time in transition:

Duration of eating disorder:

Current assessment of severity of eating disorder:

Many thanks for completing this form

SEDIG Advertisement Version 3
(06/12/2011)



Have you, or someone you care for, experienced a transition from child and adolescent services to adult services whilst receiving treatment for an eating disorder?

Would you be interested in sharing your experiences?

We are inviting service users and carers, who have experienced a move from child and adolescent to adult services in the past five years, whilst receiving treatment for an eating disorder, to take part in a research project. We are looking for participants who live within the following NHS regions: Greater Glasgow & Clyde, Lanarkshire, Dumfries & Galloway and Ayrshire & Arran.

What is the project about?

We are interested in hearing about personal experiences of the transition process and aim to explore aspects such as:

- Timing of the transition
- Feelings about the transition process
- What the good or difficult parts of this were
- How this process impacted on you

Why is this research important?

Learning more about service user and carer experiences will help us to understand how services can support other young people with eating disorders and their families during the move between services. We are hoping that with this information we will be able to make changes to improve and develop services.

What is involved?

Participation in this study will involve meeting with a researcher for a one-hour interview. This meeting will take place at the base of the NHS service that provides treatment for you or the person you care for. If travelling to this base is difficult for you it may be possible to meet at a local NHS site, such as your GP surgery, or to conduct the interview by phone. The researcher will ask you about your experience of the transition from child and adolescent to adult services. There are no right or wrong answers. It is your personal experience we would like to hear.

Who is conducting the research?

The research is being carried out by Sinead O'Loughlin and Dr Kenneth Mullen from Glasgow University, alongside Dr Christine Watson from the Eating Disorders Specialist Service in NHS Lanarkshire. If you are interested in finding out more about this project we would be happy to answer any questions you may have and will provide you with an information pack.

Contact details

Primary Researcher: Sinead O'Loughlin, Trainee Clinical Psychologist

Address: Mental Health & Well Being, Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow, G12 0XH

Phone number: 0141 211 0607 Email address: s.o'loughlin.1@research.gla.ac.uk

Appendix 2.12 Sample Semi-Structured Interview Schedule

Semi-Structured Interview Schedule for Service Users

(Version 2 – 26/08/11)

Notes for the interviewer

This Interview Schedule is to be used as a guide only and not followed verbatim.

It is important that the interviewer approach the interview with a warm and inquisitive manner. The researcher should be open to following the lead of the individual participant and their reflections around their experience. The interview schedule is structured in such a manner to allow the participant the opportunity to initiate discourse and reflection around their experiences. If the participant fails to respond or if discourse stalls the interviewer may introduce specific probes to encourage elaboration as required.

Throughout the interview, emphasis will be placed on establishing rapport and trying to understand the participant's perspective. The interviewer should at all times actively listen and reflect back to the participant, but without introducing new material to the dialogue. This will have the effect of confirming understanding, clarifying viewpoints, highlighting salient points and facilitating a rapport.

Introduction

Before we start I would like to thank you for agreeing to meet with me today. As you are aware, my name is Sinead O'Loughlin and I am a Trainee Clinical Psychologist. We are conducting a study exploring the experiences of young people with eating disorders, and their carers, when their care is transferred from Child and Adolescent Service to Adult Services. As you have experienced a transfer of care in the past five years, I would like to spend time talking to you about your experience of services and the process of transition. There are no right or wrong answers. It is your personal experience and feelings I would like to hear. If you would rather not answer a question or would like a break at any point just let me know.

Before we start, I would like to talk through the consent form with you to ensure that you understand what taking part in this study will entail and that you are happy to continue with our interview today (*each item on the consent form is to be discussed with the participant*).

I would like to remind you that our conversation will remain confidential. The only situation where this would not apply is if you told me something that made me concerned that there was a risk of serious harm to either yourself or to another person. If this happened I would be required to tell others involved in your care, such as your key-worker or psychiatrist. However, I would notify you beforehand if I was going to do this and explain why.

During our interview it is important that I listen to you very carefully so I am planning on recording the interview (*point to the digital recorder*). Nobody outside the research team will hear the tapes, and I will keep them safely locked in a filing cabinet back at the University. Are you happy for me to record our conversation?

Topic Guides with prompts (indicated by bullets)

1. Child & Adolescent Mental Health Services

I wonder if you could start by telling how you first came to be seen by Child and Adolescent Mental Health Services?

- How old were you?
- Can you remember who referred you there and why?
- How long had the difficulties existed prior to you being seen at CAMHS?

Could you tell me about your experience of receiving treatment for an eating disorder at Child and Adolescent Mental Health Services?

- What happened at CAMHS?
- Was there anything you found particularly helpful/unhelpful?
- How did you feel about the treatment approach?
- Were any members of your family involved in your treatment?
- How did you feel about family involvement in your treatment?
- Is there anything you would have liked to be different?

2. Transition planning

How did you learn that you would have to move from Child & Adolescent Mental Health Service to Adult Service?

- What were you told about the transition and by whom?
- How far in advance of the transition did you find out about it?

What was your understanding of the reasons for this move?

What did this move mean to you?

- What did you think about moving from Child & Adolescent Mental Health Service to Adult Services?
- How did you feel about the prospect of this transition?
- How did you feel about the timing of your transition?
- Were there any aspects of your eating disorder or other life events that influenced how you felt about the move at the time?

Can you tell me about any preparation you had for the move?

- How were you helped to prepare for the move? ... for example some young people may receive information about the service they'll be moving to or have the opportunity to visit the adult service and meet with their new clinicians.

Was there anything that you found helpful or unhelpful in preparing you for this transition?

- Co-ordination between services

Think back over the period leading up to your transition, is there anything that would have been more helpful in preparing you for the move or that you would have liked to be different?

3. Adult Services

I understand that you are now attending (service name)...

I understand that in the period following your transition you attended (service name)...

What's it been like going there?

- How do you feel about the approach to treatment you've experienced at (service name)?

What do you feel to be the main differences in Adult Services as compared to CAMHS?

- Are there any ways in which the treatment you receive for your eating disorder has changed?
- Do you feel that your role in treatment or others expectations of you have changed?
- Has your family's involvement in the treatment you receive changed in any way?

Are there any ways in which you found CAMHS better or more helpful than Adult Services?

Are there any ways in which you have found Adult Services to be better or more helpful than CAMHS?

4. Potential impact of transition

Do you feel that the process of moving from CAMHS to AMHS has had any effect on you?

- Autonomy
- Engagement with services
- Understanding of difficulties
- Effects on severity of eating disorder – better? worse?

Is there anything else you would like to say about your experience of transition from CAMHS to Adult Services that we haven't talked about yet?

Thank you for telling me about your experiences today and reflecting on what this transition has meant to you. We are now finished the interview, but I have some time if you would like to talk about how you found this experience or ask me any questions.

Interviewer will advise the participant that a summary of the research will be available to all participants at the end of the study and ask if they would like to receive a copy.

Examples of additional probes for all interview questions:

Can you tell me more about that?

Can you give me an example of that?

What did you think about that?

How did you feel about that?

What did that mean for you?

That sound like it's a particularly important (experience/memory/issue etc), I'd like to hear a bit more about that.

Appendix 2.13 Sample of coded interview transcripts

Service User – Becky (P10-P11)

I = Interviewer

B= Becky

Initial Notes	Text	Master Theme	Superordinate Theme
	I: And do you feel that, em, your role in the treatment has changed then?		
More collaborative approach	B: Yeah, cause like at CAMHS it was like you were just being told what to do like I was never really like asked what I wanted to do but not like I've got more options to like try things that I want to try that I feel like comfortable with.		
	I: And what does it mean for you now to have that role within the treatment.		
Increased autonomy/control. More accepting of approach.	B: I think it just helps me like it just makes me feel like I'm still in control and it's not like letting services ... I don't know it just makes me feel better knowing I can try things that I want to try and not be forced.	Autonomy	Shift in Treatment Ethos
	I: So you feel that you have a bit more control over that.		
	B: Yeah, yeah		
	I: And do you feel that the expectations then that the clinicians have, do you feel that their expectations of you are different here than maybe they were in CAMHS?		
Less emphasis on weight within treatment	B: Yeah I think so because as I say it was just about mainly about my weight at CAMHS but like I was just expected to put on weight like every time I went but it's not as much like that. Like obviously they still monitor my weight but it's not like expected that I have to put on weight every time, so...		
	I: Uh hu, so there's not the same focus just on that one area.		
	B: Yeah		
	I: And I'm wondering you mentioned your mum then use to come along to session with you. Has her role changed at all?		
Change in family role, mother less involved.	B: She doesn't come to the sessions		
	I: And how do you feel about that?		
Change in family role - mother less involved.	B: I just prefer it. I just prefer to like deal with it myself em like she's still like aware of like what's going on. I do kind of tell her things but she's just not as, she's just not got as big a role as she did at CAMHS.	Confidentiality	Shift in Treatment Ethos

Carer – Audrey (P19)

I = Interviewer

A= Audrey

Initial Notes	Text	Master Theme	Superordinate Theme
	I: I'm wondering, do you think that the process of moving from child services across to adult services has had any effect on yourself or on Freya then?		
	A: I think it's had great affect		
	I: So it's been better		
Positive impact of transition - progress	A: Seems to be fae Freya went to the adult services in here, that's when she seemed to have come on.	Development	Outcome of Transition
	I: And it sounds like her engagement with the service here has been a wee bit different		
	A: uh hu		
	I: What do you think helped with that?		
Better relationships – improved communication	A: I'm not really sure to be honest with you...I think they just listened more to Freya and what she was saying. I think that's what Freya needed. Someone to actually listen to what she was saying ...	Development	Outcome of Transition
	I: Someone to listen to her, yeah	Autonomy	Shift in Treatment Ethos
Taking her lead, more collaborative approach	A: And work ways around to help her, which she thought would be helpful rather than what they thought would be helpful. That way...I think they're good that way.	Autonomy	Shift in Treatment Ethos
	I: So to listen to her and be willing to work alongside her		
Contrast to directive approach	A: Uh hu, rather than have demands, oh you'll need to do this, you'll need do that	Autonomy	Shift in Treatment Ethos
Past resistance to directive approach (trying to assert autonomy/control in situation?) Better engagement with services now	A: When you said anything to Freya when she was in [inpatient unit], she's just resist against you, no I'm not doing it. Up here's it's sort of ... she's would listen to them cause she'd come home and say to me 'Oh I was talking about this and that aye I'm doing the right things'. She sort of listened	Development	Outcome of Transition

Major Research Project Proposal

Transition from child and adolescent to adult services in eating disorders - A qualitative study of user and carer perspectives

Matriculation Number: 0905772
Primary Researcher: Sinead O'Loughlin
Academic Supervisor: Dr Kenneth Mullen - University of Glasgow
Field Supervisor: Dr Christine Watson - NHS Lanarkshire
Word Count: 3, 568 (without references)
Word Count: 4, 462 (with references)

Structured Abstract

Background: The transition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS) in eating disorders can be challenging for young people and their families. Clinical features of eating disorders such as fear of maturity, low self esteem, high mortality rates and the increased risk associated with times of transition present unique issues for transitional care in this area. To date, there has been limited research regarding transitional care in eating disorders.

Aims: This study aims to develop an understanding of service user and carer experiences of the transition between CAMHS and AMHS in eating disorders.

Method: An interpretative phenomenological analysis (IPA) approach will be utilised in the current study. Semi-structured interviews will be employed to explore the experiences of service users and carers who have undergone a transition of care between CAMHS and AMHS whilst being treated for an eating disorder.

Applications: A deeper understanding of service user and carer experiences will offer insights into how services may support the process of transition from CAMHS and AMHS. It may highlight issues relevant to this population that are not identified within current documents addressing transitions between child and adult services. This study will contribute to the developing body of research in transitional care.

1.0 Introduction

1.1 Definitions and Prevalence Rates

Eating disorders are a group of conditions characterised by disordered eating behaviour and pre-occupation with weight and shape. They include anorexia nervosa (AN), bulimia nervosa (BN) and eating disorder not otherwise specified. Eating disorders most commonly affect young women, with the peak age of onset during mid to late adolescence. The prevalence of eating disorders amongst this population is 1-1.5%. Eating disorders are associated with significant co-morbid physical, psychological, social and occupational problems. The outcome for eating disorders is poor with an estimated 30-50% of patients developing long-term problems (Royal College of Psychiatrists, 2000; NHS QIS, 2006).

1.2 Transition between Child and Adolescent and Adult Services

Owing to age of onset and course of eating disorders, a proportion of young people and their families will experience a transition of care from CAHMS to AMHS.

There is widespread recognition that the transition from child to adult healthcare services can be problematic, with poorly defined procedures and lack of co-ordinated care planning (DoH, 2006; DoH, 2010; Kennedy, 2010; Royal College of Physicians, 2008). This area has gained increased attention in recent decades as medical advances have led to an increased life expectancy for young people with chronic illnesses, physical disabilities and learning disabilities (Swaran et al. 2010). In the latest government review of services to children and adolescents the problem of transition was identified as a critical area for policy. Kennedy (2010) reported that young people may experience transition as “a disruptive discontinuity to their care”. Moreover, many young people fall through the gap between services, failing to meet thresholds for adult service or being lost during the transition. A disruption of care during transition can negatively impact on compliance with treatment, physical health, mental well-being and engagement with services. (DoH, 2006; Swaran et al. 2010).

These transitions occur at a time when young people and their families may be experiencing significant change in other aspects of life. Adolescence is a time of increased autonomy and

individuation from family of origin. The shift in treatment ethos from child to adult services mirrors this. The systemic approach of child services, which involves parents in treatment and decision making processes, is replaced by a more individualistic model. Young people are expected to become more autonomous and assume responsibility for their healthcare (Royal College of Physicians, 2008). Research suggests that young people value having increased control of their healthcare and the opportunity to be seen independently. For parents, issues of confidentiality and consent can significantly alter their involvement in treatment. Parents have to adapt to their changing role; for some this may be experienced as a loss or they may fear relinquishing control (DoH, 2006).

Recent policy documents and guidelines have started to address transitional issues. A number of key recommendations have emerged including: early identification of those likely to require transitional care, assessing readiness for transition, sensitivity to developmental needs, working with young people to prepare for transition, promotion of self-reliance while working closely with carers and joint working between services. An overarching message is that transition from child to adult services should be viewed as a flexible process rather than a single event, the timing and length of which should individually determined (Vostanis, 2005; DoH, 2006; DoH, 2010; Kennedy, 2010; Royal College of Physicians, 2008).

Additional considerations may be required when addressing transitional issues in eating disorders. Times of transition are considered to pose an increased risk in some eating disorders (National Collaborating Centre for Mental Health, 2004) Treasure, Schmidt & Hugo (2005) suggest that the sudden change in treatment ethos, can be confusing and dangerous for young people with eating disorders and their families. Young people with the greatest severity of illness may experience difficulties with an “adult-like approach” due to fears of maturity and low self-esteem (Arcelus, Bouman & Morgan, 2008). At the same time, their parents may find that they become excluded from decisions about care. Arcelus et al. (2008) suggest that the gradual introduction of an “adult like approach” and close collaboration between CAMHS and AMHS will be vital to successful transition. The continuity of family involvement is also advised. Indeed, given the high mortality rate associated

with eating disorders, Treasure et al. (2008) advise that in cases with serious medical risks information sharing between professionals and carers is vital.

1.3 The role of carers

The role of family members in supporting individuals with mental health problems is recognised at a national level (National Framework for Mental Health, 1999). They are often the first to recognise difficulties, encourage their loved ones to seek treatment and provide ongoing support. The National Institute for Clinical Excellence Guidance for Eating Disorders (NICE, 2004) recommends that most people with AN and BN should receive treatment on an outpatient basis. Family members are considered to play a key role in recovery and it is recommended that they should normally be included in treatment of young people with eating disorders. Furthermore, family therapy is the only evidence based intervention for AN in children and adolescents (NICE, 2004; Eisler, 200; NHS QIS, 2006). These factors place the family to the fore of care in eating disorders.

Living with and providing care to someone with an eating disorder is associated with poorer mental and physical well-being, and quality of life (De la Rie et al. 2005. Treasure et al. 2001). A small number of qualitative studies have explored the experience of caring-giving in eating disorders (Perkins et al. 2004; Winn, Perkins & Murray, 2004; Highet, Thompson & King, 2005; Hillege, Beale & McMaster, 2005; Tierney, 2005). These studies have highlighted the difficulties associated with this role, although positive aspects of caregiving were also described. Carers reported that they had insufficient knowledge and skills. They wanted more information about diagnosis, and treatment, advice on how best to response to their relative and increased support. A common theme identified across studies is that the burden of caregiving is often compounded by difficulties accessing services, a lack of feedback from professionals and a feeling of exclusion from treatment. A time of particular difficulty identified by Winn et al. (2004) was the transition from CAMHS to AMHS.

1.4 Service User and Carer Perspective

The service user and carer perspective has been given increasing credence within the NHS in recent years. The Scottish government strategy “Patient Focus/Public Involvement” (NHS QIS, 2009) sets

out that we should be striving for a patient-focused NHS with service users and carers involved in planning, designing and delivering services. Achieving equity and excellence for Children similarly emphasises that the experience of children, young people and their families must be gathered so that services can be responsive to their views (DoH, 2010).

The transition from CAMHS to AMHS services in eating disorders may be experienced as challenging for young people and their families. Clinical features of eating disorders, such as fear of maturity and low self-esteem, high mortality rates and the increased risk associated with times of transition present unique issues for transitional care in this area. To date, there has been limited research regarding transitional care in eating disorders. No studies have been identified that explore the experience of transition from a service user or carer perspective. As such, it remains unclear what priorities they have for transitional care and how their needs can be best met by services. The use of qualitative methodology would be particularly suited to exploring these areas, as they aim to “understand and represent the experiences and actions of people as they encounter, engage and live through situations” (Elliot, Fischer, Rennie, 1999).

2.0 Aims

This study aims to use qualitative methods to explore service user and carer experiences of the transition between CAMHS and AMHS in eating disorders. Based on the aforementioned literature, a number of key issues have been identified that are considered important to developing a detailed understanding of service user and carer experiences of transitional care. These issues can be considered within two broad areas as outlined below.

Experience of the transition process: timing, readiness, understanding, preparation, co-ordination of process, communication between services, impact (engagement, compliance, severity of illness, carer burden)

Differences between CAMHS and AMHS: experiences with CAMHS, experiences with AMHS, treatment ethos, autonomy, role of family, information sharing, confidentiality and consent, intervention approach, adaptation to changing roles.

Semi-structured interviews will be developed based upon these themes, with the aim of identifying the most salient factors for service users and their carers.

3.0 Plan of investigation

3.1 Design

An IPA approach will be utilised. IPA is a qualitative research methodology that originated in psychology. IPA aims to explore how people make sense of their major life experiences (Smith, Flowers & Larkin, 2009). It is committed to detailed examination of individual cases, endeavouring to understand what the experience is like for the person and the meaning they assign to their experience (Smith, 2004). Researchers in IPA have a dynamic and interpretative role. They try to understand what it is like from the participant point of view, whilst asking critical questions of account to extend our understanding beyond what has been made explicit. It is advised that researchers reflect on their own conceptions and try to suspend these during the research process so that they do not overtly influence the process (Smith & Osborn, 2003).

An IPA approach has previously been used in a study exploring the transition of adolescents with Cystic Fibrosis from paediatric to adult services (Brumfield & Lansbury, 2004). The idiographic nature of IPA and focus on how people make sense of important life experiences fits with the aims of this study.

3.2 Participants

IPA literature recommends obtaining a purposive sample of participants. This refers to a predefined group of individuals who through personal experiences may provide insight into the phenomena under study (Smith & Osborn, 2003; Smith et al. 2009). Researchers generally aim to obtain a fairly homogenous sample of participants. However, Smith et al. (2009, p.49) suggest that it may be useful to split the sample so that the phenomenon can be understood from different perspectives. In the current study participants will consist of service users and carers who have experienced a transition of care between CAMHS and AMHS whilst being treated for an eating disorder.

3.3 Eligibility Criteria

Service users will be:

- Aged 16 or over with a diagnosis of AN, BN or eating disorder not otherwise specified.
- Have experienced a transition of care from CAMHS to AMHS in the past 5 years whilst being treated for an eating disorder.
- Currently be receiving treatment for an eating disorder or have undergone a planned discharge from adult services.
- Able to provide informed consent
- Deemed fit to participate by clinicians involved in their care

Carers will be:

- Individuals who are identified as the primary-caregiver for a young person who meets the above criteria.
- Able to provide informed consent

3.4 Sample Size Justification

IPA benefits from a concentrated focus on a small number of cases due to its primary concern with understanding individual experiences. Leading researchers in IPA suggest that a sample size of between four and ten participants is typically sufficient for researchers adopting this approach in a professional doctorate (Smith et al. 2009). The upper end of this sample size overlaps with guidance provided by Guest, Brunce & Johnson's (2006) on the number of participants required to reach data saturation. Based on analysis of thirty interviews, they identified that 92% of all themes were identified in the first six to twelve interviews and there was limited change to coding after this point. They suggest that in most cases six to twelve participants will be a sufficient to reach data saturation. The sample size for the current study has been determined in accordance with the above. A total of ten to twelve participants will be recruited: consisting of five to six service users and carers.

3.5 Recruitment process

Participants will primarily be recruited from CAMHS, AMHS and specialist eating disorder services in the NHS West of Scotland region. The researcher is currently involved in establishing relationships with these services. Meetings will be arranged to provide clinicians with information about this study and its aims. They will be asked to identify potential participants from their caseloads and inform them about the study. If these individuals are happy to receive further information about the study, their contact details will be passed on to the research team. Verbal consent for their details to be passed on to the research team will be documented in case notes.

Participants may also be recruited through the Scottish Eating Disorder Interest Group (SEDIG) and carers groups. An advertisement will be placed on the SEDIG website and in their newsletter, which is distributed to members. A brief description of the study and contact details for the research team will be provided. Service users and carers who are interested in finding out more about the study will be invited to contact a member of the research team. To extend recruitment of carers, clinicians in the field of eating disorders will provide details for a contact person in their local carers group or these shall be obtained via SEDIG. Initial information about the study shall be provided to this contact person and, where it is agreeable, a meeting will be arranged to provide further information to the carers group.

Potential participants will be provided with an information pack about the study. The pack will include a brief description of the study, an opt-in form indicating the best way for the researcher to contact them (i.e. phone, letter, email) and a stamped addressed envelope. Service users and carers who are interested in participating will be invited to contact the researcher by completing the opt-in form and returning it in the envelope provided

3.6 Procedure

On the basis of key issues identified in the literature, two complementary semi-structured interview schedules will be developed to explore the experience of transition between CAMHS and AMHS in eating disorders from a service user and carer perspective. Interviews will be conducted on an

individual basis. The interviews will be conducted in a flexible manner, with the option of using probes and specific questions to encourage participants to elaborate on important topics. Throughout the interview, emphasis will be placed on establishing rapport and trying to understand the participant's perspective.

Preferably, interviews will be conducted in person. However, where this is not possible telephone interviews may be conducted. It is felt important to include this option as attendance at interview may pose a barrier to participation for some individuals, particularly those who reside in rural regions. It is anticipated that interviews will last sixty to eighty minutes.

3.7 Setting and Equipment

Interviews will be conducted on NHS premises in the region where the participant resides. If participants are recruited via their key workers, it is hoped to conduct interviews on the premises of the service they are involved with.

All interviews will be recorded on a digital recorder. They will be transcribed verbatim by the principle researcher and participants will be assigned pseudonyms to ensure anonymity.

3.8 Data analysis

Transcripts will undergo analysis according to the recognised process in IPA (Smith & Osborn, 2003; Smith et al. 2009). In keeping with the idiographic approach, it is recommended that transcripts are thoroughly analysed on an individual basis before patterns across cases are considered.

The first stage of this process involves several readings of the interview transcript, to become as familiar as possible with the account. Stage two begins with noting anything of interest in the transcript. Some notes will be descriptive comments attempting to summarise or paraphrase the participant's account. Others may explore the use of language in the transcript, making note of metaphors and connections that come to mind. There may also be some preliminary interpretations, interrogating the text and taking us beyond what has been made explicit. The third stage involves the development of emergent issues, clustering and organising initial notes according to thematic content.

The sequence is repeated until a level of conceptualisation is achieved that best captures the core issues. Emerging issues will then be given a title. In the fourth stage, the researcher will attempt to make connections across the emergent issues. This process is carried out with each interview transcript and patterns across cases are then explored. The researcher is aiming to acknowledge the point of convergences and divergences in the data, illustrating ways in which participants accounts are similar but also different (Smith & Osborn, 2003; Smith et al. 2009).

Another researcher will be asked to review a selection of interview transcripts in order to verify the reliability of coding and issues that have been identified.

N-Vivo software may be used to support data analysis in the current study.

4.0 Health and Safety Issues

Interviews will be conducted on NHS premises within normal working hours. All sites at which interviews will be conducted will be assessed in terms of health and safety. A minimum requirement will be for another member of staff to be present on the premises at all times and available if required.

Written consent will be obtained from participants and they will be made aware of their right to withdraw from the study at any time. All participants will have the opportunity to discuss their experience of participation and debrief with the researcher. If there is any evidence of distress the researcher will suspend the interview and will stay with the participant until their distress decreases. If they remain distressed, other means of accessing emotional support will be discussed with the participant, such as contacting a family member or key worker.

If participants disclose information that suggests they may hurt themselves or others then steps will be taken to ensure safety and alert relevant professionals or agencies involved. Patients will be made aware of this procedure in the information sheet and at the start of the interview.

5.0 Ethical Issues

Ethical approval will be sought from the NHS West of Scotland Ethics Committee.

Participants will be provided with a clear information sheet about the study. This will state that consent is voluntary and they may withdraw from the study at any time. Participants will be informed of confidentiality and how this will be upheld. They will be advised of the process of anonymising interview transcripts so that all identifying information is removed. This will entail assigning pseudonyms to participants, with references to places and other people also being anonymised. The transcripts will be stored on an encrypted laptop and when transcribing is completed recording will be destroyed.

Those who wish to participate in the study will be required to provide written consent to involvement and consent to the inclusion of extracts from transcripts being used in the project report. It will also be highlighted that the research may be published in a scientific journal so that findings can be shared with other practitioners in this area and specific consent for inclusion of extracts will be sought for this. Participants understanding of what taking part in the study entails will be checked to ensure they are providing informed consent

5.0 Timetable

May 2011	Submit Proposal to University
July/Aug 2011	Apply for Ethical Approval
Oct/Nov 2011	Begin Recruitment & interviews
Feb/March 2012	Transcription and analysis
April 2010	Begin Write-up
May/June 2012	Draft submission
July 2012	Submit research to University
September 2012	Viva

6.0 Practical Applications

Understanding service user and carer experiences of the transition between CAMHS and AMHS in eating disorders will add to the developing body of research in transitional care. It may identify

specific issues relevant to this population that are not identified within the current policy guidelines and documents addressing transitions between child and adult services. This could contribute to the development of models that promote successful transitions in eating disorders.

References

- Arcelus, J. Bouman, W. P. & Morgan, J. F. (2008) Treating young people with eating disorders: transition from child mental health to specialist adult eating disorder services. *European Eating Disorder Review*, 16, 30-36
- Brumfield, K. Lansbury, G. (2004) Experiences of adolescents with cystic fibrosis during their transition from paediatric to adult health care: a qualitative study of young Australian adults. *Disability and Rehabilitation*, 26 (4), 223-234
- Carr, A. & McNulty, M. (2006) *The handbook of adult clinical psychology: an evidence-based practice approach*. East Sussex, UK: Routledge
- De La Rie, S.M. Van Furth E.F. De Koning, G. & Donker, M. C. (2005) The quality of life of family care givers of eating disorder patients. *Eating Disorders*, 13, 345-351
- Department of Health (2006) *Transition: Getting it right for young people – Improving the transition of young people with long term conditions from children's to adult health services*. London: DH.
- Department of Health (1999) *National Framework for Mental Health*. London: Department of Health
- Department of Health (2010) *Achieving equity and excellence for children* [Internet] Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119449 [Accessed 21 January 2011]
- Eisler I. (2005) The empirical and theoretical base for family therapy and multiple family day therapy for adolescent anorexia nervosa. *Journal of Family Therapy*, 27, 104-131.
- Elliott, R. Fischer, C. Rennie, D. L. (1999) Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229
- Guest, G. Brunce, A. & Johnson, L. (2006) How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18 (1), 59-82.
- Highet, N. Thompson, M. & King, R. M. (2005) The experience of living with a person with a eating disorder: the impact on the carers. *Eating disorders*, 13, 327-344.
- Hillege, S. Beale, B. & McMaster, R. (2006) Impact of eating disorders on family life: individual parents' stories. *Journal of Clinical Nursing*, 15, 1016-1022

Kennedy, I. (2010) *Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs*. London: Department of Health

National Collaborating Centre for Mental Health (2004) *Eating Disorders. Core Interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders. National Clinical Practice Guideline No. 9*. London: British Psychological Society & Gaskell

National Institute for Clinical Excellence (2004) *Eating disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders* [Internet] Available from: <<http://guidance.nice.org.uk/CG9>> [Accessed 05 January 2011]

NHS Quality Improvement Scotland (2006) Eating Disorders in Scotland: Recommendations for Management and Treatment [Internet] Available from: <http://www.healthcareimprovementscotland.org/previous_resources/best_practice_statement/eating_disorders_in_scotland_.aspx> [Accessed 14 March 2011]

NHS Quality Improvement Scotland (2009) Involving People Strategy 2009 – 2011. *How we will involve people in our work to improve the quality and safety of healthcare in Scotland* [Internet] Available from: <<http://www.nhshealthquality.org/nhsqis/1843.html>> [Accessed 29 January 2011]

Perkins, S. Winn, S. Murray, J. Murphy, R. & Schmidt, U. (2004) A qualitative study of the experience of caring for a person with bulimia nervosa. Part 1: the emotional impact of caring. *International Journal of Eating Disorders*, 36, 256-268.

Royal College of Physicians of Edinburgh (2008) *Think transition: Developing the essential link between paediatric and adult care*. Edinburgh: Royal College of Physicians of Edinburgh

Royal College of Psychiatrists (2000) *Eating disorders in the UK: policies for service development and training report from the eating disorders special interest group*

Smith, J. A. (2004) Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1, 38-54

Smith, J. A. Flowers, P. & Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: SAGE Publications

Smith, J. A. & Osborn, M. (2003) Interpretative Phenomenological Analysis. In Smith, J. A. (Ed) *Qualitative Psychology: A Practical Guide to Research Methods*. London : (pp 51-80) SAGE Publications.

Swaran, P. S. Paul, M. Islam, Z. Weaver, T. Kramer, T. McLaren, S. Belling, R. Ford, T. White, S. Hovish, K. & Harley, K. (2010) *Transition from CAHMS to Adult Mental Health Services*

(TRACK): A study of service organisation, policies, process and user and carer perspectives:

National Institute for Health Research Service Delivery and Organisation Programme. [Internet]

Available from <<http://www.sdo.nihr.ac.uk/projdetails.php?ref=08-1613-117>> [Accessed

18December 2010]

Tierney, S. (2005) The treatment of adolescent anorexia nervosa: a qualitative study of the views of parents. **Eating Disorders**, 13, 369-379.

Treasure, J. Murphy, T. Szmukler, G. Tood, G. Gavan, K. & Joyce, J. (2001) The experience of caregiving for severe mental illness: A comparison between anorexia nervosa and psychosis. **Social Psychiatry and Psychiatric Epidemiology**, 36, 343-347

Treasure, J. Schmidt, U. & Hugo, P. (2005) Mind the gap: service transition and interface problems for patients with eating disorders. **The British Journal of Psychiatry**, 187, 398-400

Treasure, J. Sepulveda, R. MacDonald, P. Whitaker, W. Lopez, C. Zabala, M. Kyriacou, O. & Todd, G. (2008) The assessment of the family of people with eating disorders. **European Eating Disorder Review**, 16 (4), 247-55.

Vostanis, P. (2005) Patients as parents and young people approaching adulthood: how should we manage the interface between mental health service for young people and adults? **Current Opinion in Psychiatry**, 18, 449-454.

Winn, S. Perkins, S. Murray, J. Murphy, R. & Schmidt, U. (2004) A qualitative study of the experience of caring for a person with bulimia nervosa. Part 2: carers' needs and experiences of services and other supports. **International Journal of Eating Disorders**, 36, 269-279.