RESEARCH ARTICLE

Experienced Carers Helping Others (ECHO): Protocol for a Pilot Randomised Controlled Trial to Examine a Psycho-educational Intervention for Adolescents with Anorexia Nervosa and Their Carers

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Abstract

Experienced Carers Helping Others (ECHO) is an intervention for carers of people with eating disorders. This paper describes the theoretical background and protocol of a pilot multicentre randomised controlled trial that will explore the use of two variants of ECHO for improving outcomes for adolescents with anorexia nervosa (AN) referred for outpatient care. Adolescent patients and their carers (typically parents and close others in a supportive role) will be recruited from 38 eating disorder outpatient services across the UK. Carers will be randomly allocated to receive 'ECHOc' guided self-help (in addition to treatment as usual), 'ECHO' self-help only (in addition to treatment as usual) or treatment as usual only. Primary outcomes are a summary measure of the Short Evaluation of Eating Disorders at 6- and 12-month follow-ups. Secondary outcomes are general psychiatric morbidity of AN patients and carer, carers' coping and behaviour, and change in healthcare use and costs at 6- and 12-month follow-ups. Therapist effects will be examined, and process evaluation of ECHOc will be completed. The findings from this pilot trial will be used in preparation for executing a definitive trial to determine the impact of the preferred variant of ECHO to improve treatment outcomes for AN. Copyright © 2014 John Wiley & Sons, Ltd and Eating Disorders Association.

Keywords
anorexia nervosa; Eating Disorder Not Otherwise Specified; outpatient; trial; treatment

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Background

Anorexia nervosa (AN) is a severe psychiatric illness with a protracted course (Stoving, Andries, Brixen, Bilenberg, & Horder, 2011; Wentz, Gillberg, Anckarsater, Gillberg, & Rastam, 2009) and associated with high healthcare costs (Krauth, Buser, & Vogel, 2002). The National Institute of Health and Clinical Excellence (NICE) guidelines recommend that most people with an eating disorder (ED) should be managed on an outpatient basis in the first instance (2004). The peak age of onset is in mid-adolescence (Currin, Schmidt, Treasure, & Jick, 2005; Micali, Hagberg, Petersen, & Treasure, 2013), and therefore, parents and close others usually take on a caregiving role. However, a meta-analysis of several aspects of carer functioning obtained from a systematic review concludes that carers find this role burdensome and distressing (Anastasiadou, Medina-Pradas, Sepulveda, & Treasure, 2014; Zabala, Macdonald, & Treasure, 2009). Families request information and help with this role (Haigh & Treasure, 2003).

Family therapy is one way of involving families in treatment. To date, it is the most effective form of intervention in the early phase of the illness (less than 3 years duration), according to the results of a Cochrane (Fisher, Hetrick, & Rushford, 2010b), and later, systematic review (Couturier, Kimber, & Szatmari, 2013). However, this type of involvement is less effective in those with a longer duration of illness (Fisher, Hetrick, & Rushford, 2010a). Moreover, family therapy is not acceptable for all families. Other types of interventions that involve the family have been developed such as 'separated family therapy' in which the patient is seen individually and the parents are seen in parallel (Le Grange, Eisler, Dare, & Russell, 1992). This type of intervention was as effective as family therapy and was particularly helpful for families with high expressed emotion (Eisler et al., 2000). A further adaptation is multifamily therapy (Asen, 2002). In this form of therapy, several families are seen as a group for a week (9–5). Preliminary evidence suggests that this form of intervention is as effective as family therapy (Eisler, 2005). It is, however, demanding on family time and, because of the group format, can be somewhat inflexible.

Other approaches that have been used in working with families are based on a theoretical framework with the basic assumption that if carers are provided with skills and education to understand the 'enigma' of AN, then they can form part of the therapeutic team. We have undertaken a systematic review and meta-analysis of the literature relating to this type of intervention (Hibbs, Rhind, Leppanen, & Treasure, 2014). A variety of implicit and explicit theoretical maintenance models have been employed. Thus, there have been interventions based on a form of exposure model that teach carers how to give meal support (Cairns, Styles, & Leichner, 2007; Hildebrandt, Bacow, Greif, & Flores, 2014). Others teach specific skills to promote behaviour change in carers and the sufferer, such as motivational interviewing (MI) (Goddard, Macdonald, Sepulveda, et al., 2011) or cognitive behaviour therapy (Grover, Naumann, et al., 2011; Grover, Williams, et al., 2011). Some work on the possibility that the carers coping pattern is suboptimal leading to high carer anxiety (Pepin & King, 2013); in turn, anxiety is mirrored by the person with the ED and serves to escalate symptoms (Goddard, Macdonald, Sepulveda, et al., 2011). Others are based on a model that suggests that high expressed emotion such as criticism and overprotection may maintain ED behaviours (Butzlaff & Hooley, 1998; Treasure et al., 2008). Yet others suggest that accommodation and enabling behaviours serve to maintain ED behaviours (Sepulveda, Kyriacou, & Treasure, 2009; Treasure et al., 2008). Some of the models are complex and contain all of these features. The results of the meta-analysis of carer outcomes following these forms of parenting interventions show a moderate-sized reduction in carer burden and distress, expressed emotion and accommodating behaviours (Hibbs et al., 2014, submitted). However, very few high quality studies have examined the impact of interventions offered to carers on individuals with an ED themselves (e.g. Hibbs, 2014, in preparation; Whitney et al., 2012).

Experienced Carers Helping Others (ECHO) is a novel intervention for carers based on the cognitive interpersonal maintenance model of AN (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). One element of this model is that interpersonal factors (such as those described earlier) can develop within families and maintain the illness (Schmidt & Treasure, 2006; Treasure et al., 2008). Inadvertently, these may hinder recovery. Empirical evidence to support the model is emerging (e.g. Goddard, Macdonald, & Treasure, 2011; Goddard et al., 2013). The main difference of the ECHO intervention from family-based treatment is the premise that aspects of carers' behaviour may inadvertently maintain the disorder, whereas family-based treatment is atheoretical and considers that parents have within themselves the knowledge and skills to feed their child. For example, carers are taught to assess within themselves whether they might use accommodating and enabling behaviours and react to the ED symptoms with high expressed emotion. These are modifiable behaviours, and it is thought that carers may benefit from skills training in aspects of management of EDs that are used by professionals in specialised inpatient services. Thus, the skills of MI are taught both by example and theory as a means of providing calm and compassionate meal support and engaging intrinsic motivation to change (Treasure, Sepulveda, et al., 2007). Carers are also taught how to apply behaviour change principles (e.g. goal setting and contingency management). Furthermore, carers are taught about cognitive and emotional styles associated with EDs (Schmidt & Treasure, 2006) and how to promote balanced emotional regulation and a flexible, 'big picture' style of thinking. The cognitive interpersonal maintenance model of AN (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013) includes these individual vulnerabilities such as aspects of cognitive style that are thought to contribute to the maintenance of the illness. For example, in general, people with EDs have good cognitive abilities with superior attention to detail, but they sometimes show inefficiencies in set shifting (Lang, Stahl, Espie, Treasure, & Tchanturia, 2014; Lopez et al., 2008). These traits can manifest as an obsessive–compulsive personality that is associated with a poorer response to treatment (Crane, Roberts, & Treasure, 2007). These traits are also present in people with autistic spectrum disorders, and several studies have found that people with AN have high scores on the Autism Spectrum Questionnaire (Baron-Cohen et al., 2013; Hambrook, Tchanturia, Schmidt, Russell, & Treasure, 2008; Tchanturia et al., 2013). Individuals with AN with social and communication difficulties and autistic spectrum traits have been found to have a poorer prognosis (Anckarsater et al., 2012). First-degree relatives may share obsessive–compulsive personality traits (Lilenfeld, Wonderlich, Riso, Crosby, & Mitchell, 2006). These traits may make it difficult for both the patient and carer to have a flexible response to the development of ED symptoms and worsen the prognosis.

Another facet of the cognitive interpersonal maintenance model of AN (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013) is the pro AN beliefs and behaviours that can develop as a consequence of the illness (Serpell, Teasdale, Troop, & Treasure, 2004). It is possible that these can be particularly pronounced if other members of the family have their own ED problems. There is evidence that EDs are common in first-degree relatives of patients and that EDs run across generations (Kanakam, Krug, Raoult, Collier, & Treasure, 2013; Lilenfeld et al., 1998; Strober, Freeman, Lampert, Diamond, & Kaye, 2000). Furthermore, carers' own history of eating problems is associated with caregiver distress (Goddard et al., 2013). Therefore, a family history of an ED may moderate response to treatment.

The ECHO intervention

Experienced Carers Helping Others is a guided self-help skills training intervention developed to meet some of the complex unmet needs of carers. The intervention is theory-driven and combines psycho-education with skills training by ED specialists. Initially, the elements of ECHO were delivered in the form of workshops that were found to reduce carer distress (Sepulveda, Lopez, Todd, Whitaker, & Treasure, 2008) and expressed emotion (Sepulveda et al., 2010). These also produced positive effects for the patients themselves (Goddard, Macdonald, & Treasure, 2010). As a 'next step', the training materials were synthesised into a self-help intervention (book and set of DVDs) to enhance accessibility, reduce the delivery cost and aid dissemination. Carer coaches (individuals with personal or professional experience in caregiving for someone with an ED) were trained to act as telephone mentors in order to provide guidance in the implementation of the materials. The coaches were trained to use MI as a communication style and to use the model of carer stress and the interpersonal maintenance model as a template of behaviours for possible change. This was found to be a feasible and acceptable form of intervention (Goddard, Macdonald, Sepulveda, et al., 2011); however, the 'dose' of guidance given (three sessions for one carer) was insufficient to provide benefit. A more rigorous training programme with a manual to structure the sessions and an enhanced programme of supervision and monitoring was introduced to improve the quality assurance of the intervention. The duration of coaching was increased to 10 sessions per family. In a randomised controlled trial (RCT), this was used as an intervention to support carers of patients, with severe and enduring ED, admitted for inpatient care (see Goddard et al., 2012). Following the intervention, carer burden, time spent caregiving and unhelpful carer behaviours were reduced (Hibbs, 2014, in preparation). Furthermore, patient ED symptomatology and quality of life were significantly improved in the ECHO group. There were also shorter admissions, longer time to relapse and fewer readmissions in the ECHO group (although not statistically significant). Sharing skills and information with family members and other carers was therefore of benefit for patients and carers (Hibbs, 2014, in preparation). Given that patients at this stage of illness are resistant to most forms of treatment (Hay, Touyz, & Sud, 2012; Wonderlich et al., 2012), these improvements are encouraging (Hibbs et al., 2014). A common comment from carers was the wish to have had access to the intervention at an earlier stage of the illness (Macdonald et al., in prep.).

The current trial

The primary aim of the current study is to investigate the use of the ECHO intervention (guided and not guided) for adolescents with AN at an early stage of illness. This RCT compares three treatment conditions: (i) the ECHO intervention as guided self-help (ECHOc), in addition to treatment as usual (TAU); (ii) the ECHO intervention as self-help only (ECHO), in addition to TAU; and (iii) TAU. This design will explore the additional use of coaching (the 'guided' component of guided self-help) relative to providing self-help materials alone. For carers and patients, the primary hypotheses refer to outcomes at the 6- and 12-month follow-up time points.

Methods and design

Hypotheses

Primary hypotheses

1. At 6- and 12-month follow-ups, patients with carers allocated to the intervention arms (ECHO/ECHOc) will have a more rapid and stable reduction in AN symptoms compared with those in TAU alone, as measured by the Short Evaluation of ED (SEED).
2. At 6- and 12-month follow-ups, patients with carers allocated to the guided intervention (ECHOc) will have more rapid and stable reduction in AN symptoms compared with those in ECHO only (ECHO), as measured by the SEED.

Secondary hypotheses

3. The cost of support (societal and individual) will be lower for patients and carers in the ECHO/ECHOc arms than those in the TAU group at 6- and 12-month follow-ups.
4. Carers who receive ECHO/ECHOc will report a greater reduction in caregiving burden [objective (i.e. contact time and family expenditure related to AN) and subjective (i.e. distress)], and accommodation and enabling, compared with those with TAU at 6- and 12-month follow-ups.
5. A reduction in accommodation and enabling behaviours and caregiving burden will mediate outcomes for patients.
6. Obsessive–compulsive and autistic traits in patients and carers will moderate the effect of ECHO/ECHOc on carer and patient outcomes.
7. Parental attitude and behaviour towards food, weight and shape will moderate carer and patient outcomes.
8. ECHOc will be delivered to an acceptable level of competence, as measured by the Motivational Interviewing Treatment Integrity (MITI 3.1.1) (Moyers, Martin, Manuel, Miller, & Ernst, 2010).
9. There will be therapist effects (level of experience and carer coaches *versus* professional affiliation coaches) on the efficacy of ECHOc coaching intervention.

Research plan

Trial design

This is a pragmatic three-arm multicentre parallel group pilot RCT. The study design is shown in Figure 1. Consenting carers of patients who meet the eligibility criteria will be randomly allocated to receive ECHO (in addition to TAU), ECHOc (in addition to TAU) or TAU only. The delivery of ECHO and ECHOc is managed by the coordinating centre. Patients and their carers will be recruited from adolescent and ED National Health Services (NHS) providing ED specialist outpatient care to individuals with an ED aged 13–21 years inclusive across the UK. This evaluation will investigate ECHO and ECHOc in a pragmatic setting, reflective of outpatient care for ED in the UK. Data will be collected at baseline (referral to outpatient services) and follow-up time points (6 and 12 months).

Randomisation

Carers are randomly allocated to one of the three trial arms (ECHO, ECHOc or TAU) within 24 hours of completion of family baseline assessment. Randomisation is carried out using the King's Clinical Trials Unit's independent web-based system (King's College London, London, UK) and managed only by the two lead researchers (C. R. and R. H.). A database will hold the basic details required for randomisation [centre, severity of illness (weight/height, presence of compensatory behaviours and presence of previous hospital admissions), date of birth, initials and unique patient number]. Stratified randomisation using centre (3+) and illness severity (weight/height ratio) and minimisation with a random component is used. The first *n* cases (*n* will not be disclosed) are allocated randomly to further enhance allocation concealment. Randomisation can only be carried out by the lead researchers, and details are locked following group allocation. The stratification factors (study site, age and illness severity) will

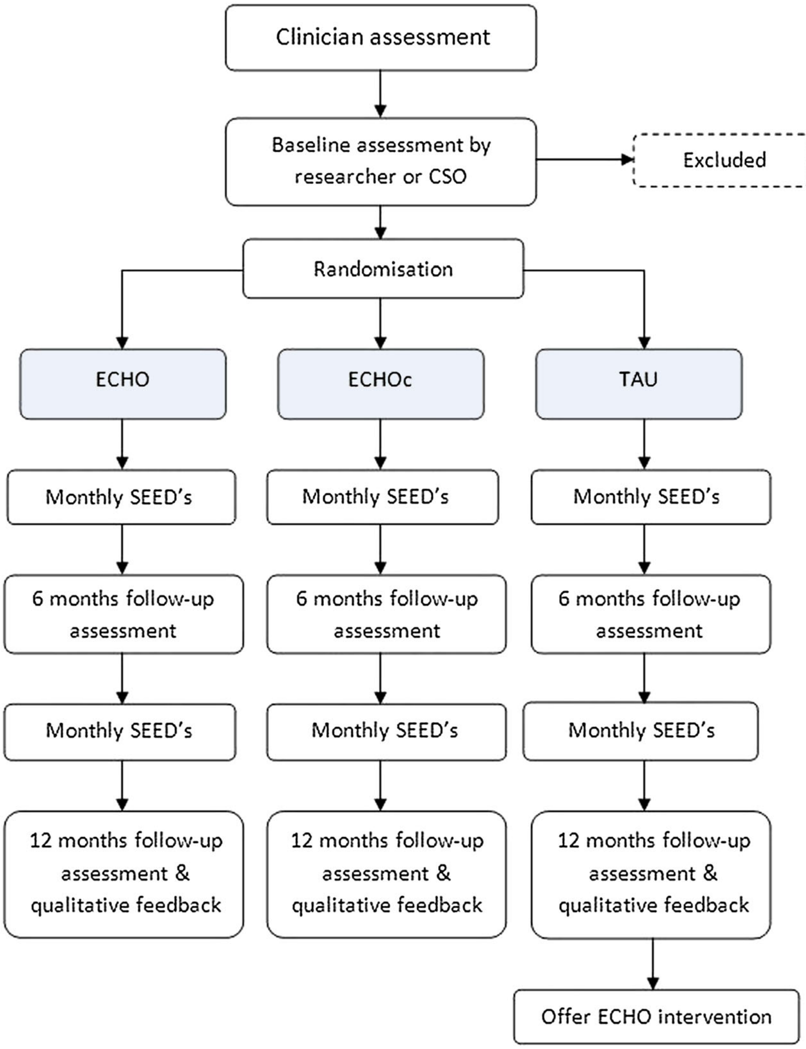

Figure 1. Study design. ECHO, Experienced Carers Helping Others; ECHOc, the ECHO intervention as guided self-help; TAU, treatment as usual; SEED, Short Evaluation of Eating Disorders; CSO, Clinical Studies Officer

be adjusted for in the analysis. All correspondence with carers on randomisation is by post. All coaches will be contacted simultaneously for each participant randomised, and families are allocated on a first-come-first-served basis. Information concerning participants will not be shared with the coaches prior to allocation.

Researcher blinding

This is a single blind study. The two lead researchers (C. R. and R. H.) are individually responsible for managing the randomisation of a selection of the participating sites and blind to the group allocation of those managed by the other. Assessment is coordinated so that researchers will only conduct interviews with those for whom they are blind to treatment allocation.

Participating sites

This project is a multicentred trial involving 38 UK ED services providing outpatient care for people aged 13–21 years inclusive. Seventeen of the sites are Child and Adolescent Mental Health Services (CAMHS), 13 are adult services and 8 have both CAMHS and adult teams recruiting. All sites are managed within the NHS (public sector).

Participants

Patients newly referred to an ED outpatient service, with a primary diagnosis of AN or ED not otherwise specified AN type (EDNOS-AN) according to the DSM-IV criteria (APA, 1994), and aged between 13 and 21 years are invited to participate. The DSM-IV was chosen as the diagnostic tool currently in use at the time of planning the trial. Age bounds were chosen to represent an adolescent sample up until brain development comes to completion (early twenties) (Keverne, 2004) and usually whilst in full-time education. This is also consistent with previous similar adolescent trials (Schmidt et al., 2007). At least one carer (typically parent/s) living with the patient currently and for the next year, identified by the patient, must participate for the family to be included in the study. Other close carers are encouraged to take part also. "Carers" are defined by criteria of the Princess Royal Trust (www.carers.org) as someone who provides unpaid help and support to a parent, child, partner, relative, friend or neighbour. Patients need to be fluent in English and are excluded if they or their carers are taking part in another treatment. Further exclusion criteria were severe comorbidity at time of admission (e.g. severe learning disability and psychosis). No formal sample size calculation was completed because this is a pilot RCT and will be used to obtain information on the likely effect size, variability and other aspects of outcome data for a future definitive trial sample size calculation. As achieved in the previous Carer Assessment, Skills and Information Sharing trial, we estimate that it is feasible to randomise 175 families over the planned 18-month recruitment phase.

Recruitment

Patients will be approached by clinical staff at the participating sites on initial assessment and given information about the study. Written assent will be collected for all patients and written and informed consent from their parents or guardians and all other participating carers. Clinical studies officers from the Mental Health Research Network (MHRN) support recruitment of patients and data on participant flow are collected according to Consolidated Standards of Reporting Trials recommendations (Moher et al., 2010). Participants are entered into a prize draw for taking part in the study. They are not reimbursed or paid for participation.

Treatment arms

Experienced Carers Helping Others

Participants allocated to ECHO will receive the self-help version of the intervention. This is offered as an additional resource to treatment offered by clinical teams and is not designed to replace any aspects of individual or family therapy. ECHO uses an educational and skills training approach and consists of self-help materials developed for parents, siblings, partners and other carers of someone with an ED. Materials are posted to carers and include a book co-authored by a professional, a carer and an individual with an ED (Treasure, Grainne, & Crane, 2007), a series of video clips that illustrate the principles described in the book (see Sepulveda, Lopez, Macdonald, & Treasure, 2008 for description of DVD content) and a short guide for carers as a further supplement to the book. ECHO utilises several strategies that have been identified as important for the success of behaviour change interventions (Michie, van Stralen, & West, 2011).

Coaching with ECHO (ECHOc)

In addition to the self-help materials, the ECHOc intervention package includes 10 telephone coaching sessions with 'experienced coaches' trained to deliver ECHOc. Coaching sessions will be allocated, where possible, between participating carers (e.g. mother and father). Participants will be contacted by the coach within two weeks of receiving the material by post. Coaches are asked to complete the sessions within a 5-month period. Calls can therefore be regular with a time lapse (e.g. two weeks) for carers to practise the skills. Calls are approximately 40 minutes in length, and carers receive a minimum of six calls (per family) to have completed the intervention.

Motivational interviewing (MI) is the primary therapeutic tool used to deliver the telephone coaching (Rollnick, Butler, Kinnersley, Gregory, & Mash, 2010). MI is defined as 'a collaborative, person-centred form of guiding to elicit and strengthen motivation to change' (Miller & Rollnick, 2009 p. 137). The spirit of MI is empathic, deferential and curious. Coaches are trained to promote change through recognition of ambivalence in the individual, reflective listening and eliciting change talk, as detailed in Table 1. Coaches utilise behaviour change principles such as those outlined in the NICE guidelines (2007), for example, setting of action plans (considering goals and obstacles) for commitment to behaviour change. Carers are also taught MI skills to initiate change with the person for whom they are caring.

Telephone coaches. The telephone coaches are 17 individuals with professional ($n = 7$) or lived (personal or carer) experience of ED. Inclusion criteria for coaches are people with lived or professional experience of ED with sufficient time and access for the training, supervision and coaching. Further inclusion criterion, but not a requirement, is previous participation in carer interventions and training in professions allied to medicine, or equivalent (psychology and counselling) or teaching. It is required that carer coaches' loved ones with an ED are stable or in a maintenance phase of the illness, and those with an ED personal history must describe

Table 1 Description of maintaining factors targeted by the intervention

Maintaining factors and how they are targeted in the carer skills interventions	
Anxiety, depression	Pleasant activity scheduling, social support. Emotion-focused therapy, compassion-focused therapy, self-care, self-nurturing
Guilt and shame	Education about illness Contact with other carers. Self-reflection regarding getting support for self, medication, counselling
Rigidity, compulsivity, preoccupation with detail, eating	Education and feedback. Remediation to ameliorate extreme traits
Misperceptions and misunderstanding of eating disorders	Education about illness Contact with other carers. Online support groups, websites. Skill-based Learning book
Enabling and accommodating to the illness	Functional analysis. Training in communication, and problem solving
Expressed emotion (criticism, hostility and overprotection)	Education about 'transference' issues. Education about expressed emotion animal models
Unhelpful communication	Motivational interviewing

themselves as recovered for at least two years. Exclusion criteria are having a family member with AN who remains acutely ill and English nonfluency.

Eleven coaches were recruited from the earlier RCT 'Carer Assessment, Skills and Information Sharing' (see Goddard et al., 2012), and the remaining coaches were recruited internally within the department as professionals and patient and public involvement members who expressed interest and met inclusion criteria. The telephone coaches are 17 individuals with professional ($n = 7$) or lived (personal or caregiving) experience of ED. Coaches were offered payment for their time, and running costs were reimbursed.

Treatment fidelity and quality assurance (ECHOc). All experienced coaches receive didactic training (eight face-to-face days) in MI and in the ECHO model based on the intervention book and DVDs. Experienced coaches are closely supervised with training cases (outside the study). They can only take on study participants once they have obtained a minimal level of competence as assessed by expert supervisors using the MITI 3.1.1 rating measures (Moyers et al., 2010). The coaching sessions are audiotaped, and sessions 3 and 7 are transcribed and coded using the MITI 3.1.1 to assess treatment integrity and fidelity. Feedback generated by the MITI 3.1 is also used for the purposes of supervision and ongoing training. Coaches may access further supervision on demand. The level of background experience of the experienced coaches varies, but the self-directed aspects of training allow for variable levels of practice and review. Coaches are required to give a brief overview of each session in a session record form for each family and complete the Positive and Negative Affect Scale (Watson, Clark, & Tellegen, 1988) twice per family (sessions 3 and 7) before and after the session.

Treatment as usual

The NICE guidelines have one Grade B and several Grade C recommendations for the treatment of AN in adolescents and young adults (2004). Accordingly, most people with AN should be managed on an outpatient basis with psychological treatment and physical monitoring provided by a healthcare professional competent to administer care and assess physical risk. NICE recommends this combination of treatment for at least 6 months duration, with more intensive forms of treatment to be considered in cases of significant deterioration, nonimprovement or in cases of physical risk. Weight restoration in an outpatient setting should aim for an average weekly weight gain of 0.5 kg, and for adolescents, family interventions that directly address the ED should be offered (grade B). Furthermore, when treating adolescents, family involvement should be encouraged because of the effects of AN on other family members. Meanwhile, individual appointments (separate from family members or carers) should be made available to the patient.

The treatments delivered at each centre differ, for example, the amount of contact time between patients and carers with professionals. The profile of each service is captured by Service Information Schedule (SIS) (detailed later). A variable describing the amount of direct carer-professional contact will be used as a covariate.

Those allocated to the TAU arm will be informed that they will have access to the intervention on completion of the study and given contact details for Beat, the leading UK ED charity.

Outcome measures

Participants (patients and carers) will complete assessments at baseline and over the course of 1 year by telephone interview and self-report by post or email. The assessments measure key outcomes and prognostic variables.

Patient assessments

1. Clinical and demographic information (baseline)
2. The SEED (Bauer, Winn, Schmidt, & Kordy, 2005) is a valid and reliable measure developed for the repeated measurement of ED symptoms over time. Regular monitoring allows identification of patterns of change and events during treatment (e.g. rapid response to treatment) that can contribute towards the further planning and development of complex interventions. The SEED assesses ED symptoms over the past week and can be completed as clinician interview or by self-report. Unlike the Eating Disorder Examination (Cooper & Fairburn, 1987), the SEED does not distinguish clearly between different aspects of attitudinal components; however, it provides a short measure that is quick to administer (5 minutes completion time) and sensitive to change. The SEED is scored by means of an algorithm including weight and key symptoms (baseline and monthly for 1 year).
3. The ED and Autistic Spectrum Sections of the (computerised version) Development and Well-being Assessment (DAWBA; www.dawba.com) (Goodman, Ford, Richards, Gatward, & Meltzer, 2000) are validated semi-structured assessments completed by an informant (primary caregiver) and the individual themselves. Preliminary clinical diagnoses [according to DSM-IV (APA, 1994), and ICD-10 (WHO, 2010)] are derived by an internal computer algorithm. An experienced clinical rater (N. M.) then reviews these, taking into account open-ended comments, and assigns a final diagnosis (baseline, 1 year).
4. The Social Aptitude Scale (Liddle, Batty, & Goodman, 2009) is a 10-item assessment instrument, completed by an informant, as part of the DAWBA. It measures skills in social understanding and behaviour. A cut-off score of 16 (lower scores indicate poorer social aptitude) is associated with sensitivity of 0.93 and specificity of 0.93 for the diagnosis of autism spectrum disorders. A modal score of 20 was found using data from a large epidemiologically based study of young people in the UK (http://www.dawba.com/SAS) (baseline, 1 year).
5. The Strengths and Difficulties Questionnaire is a well-validated 25-item questionnaire, completed by an informant and by the individual themselves, as part of the DAWBA. It is composed of five scales that assess behaviour problems, hyperactivity, emotional symptoms, peer problems and prosocial skills (Goodman, 2001). The sum of the first four subscale scores forms a total difficulties score. Ratings of child distress and the impact of difficulties on social capital form a total impact score. A follow-up version assesses change in difficulties, using a five-point Likert-type scale (www.sdqinfo.com) (baseline, 1 year).

6. The Clinical Impairment Assessment 3.0 (Bohn & Fairburn, 2008) is a 16-item scale to assess ED-related impairment on psychosocial functioning (baseline, 1 year).
7. The Depression, Stress and Anxiety Scale 21 (Lovibond & Lovibond, 1995) is a 21-item self-report measure of emotional symptoms (depression, anxiety and stress) validated in both clinical and nonclinical samples with good internal reliability (baseline, 6-months, 1 year).
8. The Children's Yale-Brown Obsessive–Compulsive Scale Self-report (Piacentini, Langley, & Roblek, 2007) measures presence and severity of obsessive–compulsive symptoms. It is a self-report version of the Gold Standard interview measure for obsessive–compulsive disorder (Scahill et al., 1997) (baseline).
9. The Brief Dyadic Scale of Expressed Emotion Patient Version (Medina-Pradas et al, unpublished) is a 14-item scale to measure patients' perspectives of levels of expressed emotion of their carers. Three subscales measure perceived criticism, perceived emotional involvement and perceived warmth. The scale is completed separately for each participating carer (baseline, 6 months).
10. The Treatment Satisfaction Questionnaire (Roots, Rowlands, & Gowers, 2009) is an established instrument rating prior expectation of, and motivation to participate in, treatment they have received (randomised or not) on a Likert scale. The measure includes an area for free expression about any aspect of the services they have received (baseline, 6 months).
11. The Client Service Receipt Inventory (CSRI) is a well-established interview method of data collection, linked to cost analysis (Beecham & Knapp, 1999). A brief version is developed for this study, to document each young person's use of specialist and generic health services and education or employment (baseline, 6 months and 1 year).

Carer assessments

1. Clinical and demographic information (baseline)
2. The Depression, Anxiety and Stress Scale (Lovibond & Lovibond, 1995); see earlier discussion for details (baseline, 1 year)
3. The General Health Questionnaire 12 (Goldberg, 1972) is a well-validated 12-item measure assessing general well-being over the previous few weeks using a four-point Likert scale (baseline, 1 year).
4. The Family Questionnaire (Wiedemann, Rayki, Feinstein, & Hahlweg, 2002) is a 20-item self-report measure of expressed emotion in carers. Scores are given on a four-point Likert scale and form two subscales: emotional over-involvement and criticism. Good internal consistency is reported (Wiedemann et al., 2002) (baseline, 6 months).
5. The Accommodation and Enabling Scale for EDs (Sepulveda et al., 2009) is a 33-item self-report measure including five subscales: avoidance and modifying routine, reassurance seeking, meal ritual, control of family and turning a blind eye. Internal consistency for the scale is good (baseline, 6 months).
6. The Autism Quotient 10 (Allison, Auyeung, & Baron-Cohen, 2012) is a 10-item self-report version of the original Autism Quotient instrument measuring social skills, attention switching, attention to detail, communication and imagination. A cut-off point of 6 is indicative of autistic spectrum disorder (baseline).
7. The Obsessive–Compulsive Inventory—Revised (Foa et al., 2002) is an 18-item self-report measure that assesses the frequency and associated distress of six obsessive–compulsive symptom domains and a cut-off point of 21 indicative of obsessive–compulsive disorder (baseline).
8. Family Meal Patterns (Neumark-Sztainer, Wall, Story, & Fulkerson, 2004) selected questions are included to assess attitudes to eating, weight or shape within the family and family eating patterns (baseline).
9. The Treatment Satisfaction Questionnaire (Roots et al., 2009), as discussed earlier (baseline, 6 months)
10. The CSRI (Beecham & Knapp, 1999), as discussed earlier. Also details additional expenses for them or their family as a consequence of AN (baseline, 6 months and 1 year).

Primary outcomes

The primary outcome is the rate of change of a summary symptom score measured at 6- and 12-month follow-up from the SEED. Weight data at assessment are obtained from the outpatient team and thereafter via a monthly telephone interview (SEED) with patients. In cases where patients themselves feel or are unable to complete the SEED, consent to contact a professional who regularly records their weight will be obtained.

Secondary outcomes

Secondary outcomes include general psychiatric morbidity of AN patients and carer, carers' coping and behaviour, and change in healthcare use and costs at 6 months (end of treatment) and 1 year (follow-up), between groups (ECHOc, ECHO and TAU). These include group difference in change from baseline in

- DAWBA diagnosis at 1 year
- Clinical Impairment Assessment scores in AN at 1 year
- health and social costs at 6 months and 1 year
- depression, anxiety and stress in AN and carers measured at 1 year
- expressed emotion (Family Questionnaire) and accommodation and enabling behaviours (Accommodation and Enabling Scale for EDs) at 6 months. Change in these scores as mediators of outcome for both carer and patient
- carer and patient obsessive–compulsive and autistic traits as moderators of outcome
- familial eating patterns and attitudes as moderators of outcome

Process evaluation

Acceptability of ECHOc will be assessed using a visual analogue scale completed by carers. The utilisation of ECHOc will be assessed using a self-report measure asking carers and coaches to rate the amount of the book read, DVDs watched and number of telephone sessions received. Carers will be asked to rate their coach across different dimensions and the utility of the intervention for specific areas of interest (e.g. responses to the ED, communication and own distress). We will examine how quality impacts on outcome, in order to determine how quality should be assessed and controlled in the definitive trial.

Economic evaluation

Service Information Schedule (SIS): The SIS is used to record details of staff grade and time use, travel and other expenses, materials (book, DVDs and recording devices) as well as training and supervision provided to telephone coaches. These data allow estimation of the unit cost of the ECHO intervention. Staff costs will include salary overheads.

The CSRI (Beecham & Knapp, 1999) is a well-established resource-use schedule. It has been specifically adapted for this evaluation, to record patients' and carers' service use over the 6 months prior to each interview, distinguishing service use related to AN and for other reasons. Out-of-pocket expenses, social security benefit receipt and absences from work or education are also recorded, as is reduced work productivity and the impact of AN on their daily routine.

Observed confounding variables

The following patient (P) and carer (C) variables will be included into statistical models as potential confounding variables:

- demographic information (P, C): self-report gender, age, marital status, education level and employment status
- ED history (C): a binary (yes/no) question about whether the carer has a history of difficulties with eating/shape/weight
- illness severity (P): duration of illness, lowest lifetime body mass index (BMI), comorbidity and number of previous hospital admissions due to their ED. Current BMI and whether they use vomiting as a compensatory behaviour will also be included (randomisation stratification). All will be entered as separate possible confounders
- treatment (P): centre of treatment will be coded.
- readiness to change (P): patients are asked to rate the importance of and confidence to change their ED on a Likert-type scale (0–10).
- contact time (P, C): amount of face-to-face and other contact and whether carer and patient are living together
- carer involvement (P, C): frequency of carer involvement in treatment and support received (e.g. carer support groups), number of carers involved and binary variable for whether both parents are involved (yes/no).

Statistical analysis plan

Outcome analysis

All main analyses will follow the 'intention to treat' principle; that is, patients will be analysed in the groups to which they were randomised irrespective of treatments received.

A summary approach will be taken. Because this is a pilot trial, we do not anticipate having sufficient numbers to use repeated measures models. The time trend in AN symptoms as measured by SEED over 12 months for each person will be estimated using an appropriate method, and effect sizes will be calculated; for instance, a linear regression model will be used if the trend is linear over time (we will explore other models if this is not the case). The parameter from these models that estimates the trend over time (i.e. the slope parameter) will be extracted for each person. The difference between the groups in the rate of change over time will then be examined by means of an analysis of variance test applied to these summary parameter data. Tukey's correction will be used to adjust for multiple statistical tests.

Economic evaluation

The number of contacts with healthcare services will be compared. In addition, a unit cost for each service will be estimated using a compendium of nationally applicable data (Curtis & Netten, 2008) or using an equivalent methodology, including that for the interventions. Costs per case will be calculated as the unit cost multiplied by the use made of each service over the 3 months prior to interview with repeat measures at 6 and 12 months. Costs of ECHOc will also be estimated to include training, supervision and number/duration of contacts with each carer.

Discussion

The aim of this pilot trial is to investigate the use of the ECHO intervention (guided and not guided) for adolescents with AN or EDNOS-AN at an early stage of illness referred for outpatient care. The intervention is based upon an interpersonal maintenance model of EDs (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013) and represents the next step in a series of experimental studies developing ECHO. This study will be the first to investigate the use of guided skills training for carers of adolescent sufferers, most of whom are at the early intervention stage (i.e. initial stage of the illness), by using quantitative measures for both patient and carer outcomes. The design of this intervention is novel, as the needs of family members themselves have not been taken into account in the field, despite the high levels of dependence and disability associated with AN.

Limitations and challenges

First, the necessity to involve both patients and carers may have a negative effect on the accrual rate. However, this is a novel aspect of the study, as the well-being and costs of care by parents of adolescents with AN have not been considered previously. We anticipate that the assessment procedure will seem burdensome at times, and we will accommodate participants' needs where possible (e.g. alternative reliable correspondence for weight data). We anticipate that the families who are allocated to TAU may be disappointed and may not adhere to follow-ups. We will strive to minimise this by offering carers the intervention materials on completion of the project and by sending regular newsletters and personalised reminders, birthday greetings and others. An additional difficulty with the design of the trial is the heterogeneity in treatment provision across treatment centres, and individuals and families will vary in their level of engagement in treatment programmes. This heterogeneity is acknowledged in the use of pragmatic trial design and a randomised procedure that stratifies by treatment centre. Furthermore, the record of services used on the CSRI will help identify any differences between the areas. The level of motivation, receipt of individual treatment and family involvement in treatment can be included in the analysis.

Training and support for telephone coaches is another challenge, as coaches are themselves volunteers and cannot commit to the level of training and supervision that other professionals may receive. In addition to the supervision offered in different formats (e.g. telephone, email and face to face) and quality control, we will share new developments through the website developed by P. M. www.thenewmaudsleyapproach.co.uk We will also provide annual conferences for carers (with special sessions for the carer coaches) to enable them to meet the team face to face and to also place their participation in the research into the larger context of research and development in this area. The carer coaches will also be invited to more specific training held at South London and Maudsley NHS Foundation Trust for professionals. Members of the research team will also accept invitations to talk about the study at the local recruitment sites.

Conclusion

This paper outlines the protocol for a project that will add to the small literature base on interventions for AN and EDNOS-AN, focusing on adolescents at the early stage of illness. We have outlined the components of the ECHO intervention and clearly stated the research methodology in accordance with recommendations that will improve reporting and replication of treatment evaluations (Glasziou, Meats, Heneghan, & Shepperd, 2008; Moher et al., 2010). We hope that the findings from this study will determine the parameters for, and be used to execute, a definitive trial. Overall, we hope to pave the way for more integrated and collaborative interventions that have the potential to improve outcome in AN and EDNOS-AN at a small cost to services.

Trial registration

ISRCTN83003225—ECHO

Ethics and governance

Main ethics approval has been granted by the Northwick Park Hospital Ethics Committee (11/H0724/4). Site-specific ethics and governance approval has been granted on all participating sites and this study adopted by the MHRN.

List of abbreviations

ED, eating disorders; AN, anorexia nervosa; EDNOS-AN, Eating Disorder Not Otherwise Specified, Anorexia Nervosa subtype; ECHO, Experienced Coaches Helping Others; RCT, randomised controlled trial; NICE, National Institute of Health and Clinical Excellence; MI, motivational interviewing.

Competing interests

J. T. is an author of the book used in the ECHO intervention (Treasure et al., 2007). R. H., C. R., E. G., P. M. and G. T. provided coaching in the ECHOc treatment arm.

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