Evaluation of a novel transition support intervention in an adult eating disorders service: ECHOMANTRA

Journal:	*International Review of Psychiatry*
Manuscript ID	Draft
Manuscript Type:	Original Research
Date Submitted by the Author:	n/a
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Keywords:	Anorexia Nervosa, Eating Disorders, Transitions, Intervention, Carer, MANTRA, ECHO, Length of stay, NICE, Inpatient Hospital

Title Page

Evaluation of a novel transition support intervention in an adult eating disorders service: ECHOMANTRA

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Abstract (max 200 words)

Background: Admissions and re-admissions for inpatient care for anorexia nervosa have been increasing. The aim of this study was to examine whether the transition from inpatient care to the community could be facilitated by supplementing usual treatment with ECHOMANTRA (transition interventions) for both patients and carers.

Method: A case series study using a mixed-methods approach to measure the feasibility and efficacy of augmenting intensive hospital treatment with ECHOMANTRA. A consecutive series of consenting patients (n=31) and carers (n=21) were assessed on admission, discharge and at three months follow-up. These outcomes were compared with audit data (n=152) previously collected (2007-2017).

Results: Length of stay for the ECHOMANTRA intervention group was 4.5 weeks less than the comparison group and weight gain was 0.11kg per week higher. Improvements in patient symptomology were sustained at follow-up. Thematic analysis of the feedback from both patients and carers suggests that the intervention is valued. Carer burden was reduced and their skills improved (both moderate size changes).

Conclusion: Both the acceptability and efficiency of inpatient care for anorexia nervosa may be improved by augmenting treatment to prepare for transition from inpatient care by giving support to both patients and their carers.

Introduction

Anorexia nervosa (AN) is a severe mental illness typically developing in adolescence (Herpertz-Dahlmann, 2009) and has the highest mortality rate of any mental disorder (Arcelus, Mitchell, Wales, & Nielsen, 2011). The prevalence of AN is rising and inpatient admissions have increased (NHS Digital, 2017). Furthermore, the length of stay (LoS) in hospital is higher than for any other adult psychiatric disorder and the annual NHS England (UK national funding body) costs are estimated at up to £230 million (NHS Digital, 2017; Warnke & Rössler, 2008). The most recent National Institute for Health and Care Excellence (NICE) guidance emphasises the risk of institutionalisation of patients with AN in inpatient settings and questions whether prolonged admissions may be harmful (NICE, 2017). However, liaison between inpatient and community teams, who may not have specialist expertise and may be some distance away, can be difficult. Unresolved complexities during the transition phase, such as attachment to the inpatient environment and loss of social networks, may adversly impact on continuity of care and the ability to sustain the changes made in inpatient settings (Smith et al., 2016).

The symptoms of AN are pervasive and intrusive into family life. Moreover the disabilities associated with severe and enduring AN often means that the individual has difficulty with independent living and needs to rely on family support. However, in adult services, family members are often excluded from treatment, often due to concerns around confidentiality. BEAT, the largest eating disorder charity, has called for families to be included, whenever possible, and informed about how to help. Family Based Therapy can be effective in reducing relapse in the early phases of adolescent onset (Eisler et al., 2016; Godart et al., 2012; Russell, Szmukler, Dare, & Eisler, 1987) however, it is less effective in adults or those with a more chronic form of illness (Russell et al., 1987). Through a process of iterative co-working with patient and public involvement (PPI) and following the MRC Framework for the development of complex interventions (Craig et al., 2008), we have developed an intervention for carers that addresses the needs of this hard to treat group (ECHO: Experienced Carers Helping Others; Treasure, Rhind, Macdonald, & Todd, 2015). This targets some of interpersonal maintaining factors that arise as a consequence of the illness and aims to increase social connection (Treasure & Nazar, 2016). Augmenting both inpatient and adolescent outpatient treatment with ECHO for carers, not only reduces carer burden and distress but also reduces re-admission rates and symptoms in patients (Hibbs, Magill, et al., 2015; Hodsoll et al., 2017; Magill et al., 2016).

There has been interest in using digital approaches to improve the process of transition for individuals. A German randomised controlled trial (RCT) (n = 258, AN participants) compared an internet-based cognitive–behavioural relapse prevention programme with treatment as usual (TAU) and found that symptom change was sustained in the intervention group (Fichter et al., 2012). In a NHS setting, a small pilot study of a guided self help intervention (based on the MANTRA Maudsley model of AN treatment for adults manual (Schmidt et al.,2018)) showed some promise to support transitions from inpatient care (re-admission rates were five out of 22 (22.7%) in the experimental group and five out of 16 (31.2%) in the TAU alone group (Sternhem et al., 2017)). Furthermore, we augmented the transition into outpatient care with a short, online, adaptation of MANTRA (*recovery* MANTRA) as an early phase supplement to outpatient treatment for AN (Cardi et al., 2015). This increased motivation and improved engagement in treatment with an improvement in the therapeutic alliance (Cardi et al., in prep).

Given the chasm in care that can open at discharge from an inpatient setting, we developed an intervention that supplemented treatment, by planning for an increase in social support over the transition period. The cognitive interpersonal model (Treasure & Schmidt, 2013) which underpins both ECHO and MANTRA, predicts that improving interpersonal relationships through targeting both patient and carer processes would produce better traction for change and foster collaboration between patients, carers and staff to bridge the transition from hospital to home. The current project combined these two intervention modalities by providing ECHO to friends and family and *recovery* MANTRA to patients. A mixed-methods approach was used to evaluate the feasibility and acceptability of this novel transition support intervention (ECHOMANTRA). Our hypothesis was that the process of discharge would be easier (reducing the duration of inpatient care) and that outcomes would be sustained post-discharge. An additional hypothesis was that carers confidence and skills would be increased and that carers would feel less burdened, demonstrated by an improvement in their self-reported outcome measures.

Method

Participants

Participants with AN were recruited from the national eating disorders service at the Bethlem Royal Hospital between January 2017 and January 2018. All admissions to the inpatient unit were assessed for eligibility and offered the chance to participate in the ECHOMANTRA intervention. Exclusion criteria were insufficient knowledge of English and a severe mental or physical illness needing treatment in its own right (e.g. psychosis or diabetes mellitus). Out of 62 admissions during the recruitment period, five of those being re-admissions, 31 patients consented to take part in the study. Once patients consented they were invited to include a nominated carer. Out of the 31 patients, 21 carers consented and completed the baseline questions. Seven carers did not complete the baseline questions or did not consent whilst three patients did not want any family or carer involvement. All patients were female with a diagnosis of AN and carers were 80% parental and 20% other relationships. 15 patients and 10 carers completed a semi-structured telephone interview following completion of the follow up questionnaires. (Fig. 1) demonstrates participant recruitment map throughout the study.

INSERT FIG. 1 HERE

Study Design

ECHOMANTRA was designed to be delivered as an adjunctive intervention to TAU. TAU comprised of nutritional and medical interventions as well as individual and group psychotherapy. We used a repeated-measures evaluation of the feasibility and effectiveness and of the ECHOMANTRA intervention. Participants and their carers were given the intervention following consent. Ethics approval was granted by Camberwell St Giles Research Ethics Committee London (Reference 16/LO/1137).

ECHOMANTRA Intervention

ECHOMANTRA includes video-clips and workbooks and aims to sustain a recovery identity after discharge. Patients received weekly guided self-help sessions, joint meals with their carer and graduated leave planning with the team. All patients received a minimum of five guided self-help sessions with homework between sessions and experiential home leave practice with review sessions. Patients and carers were also offered a minimum of two practice meals using a stepped hierarchy approach with guidance and advice from experienced staff. Integrating carers into inpatient treatment was at the core of ECHOMANTRA and was facilitated by the collaborative approach to treatment. This meant involving carers in meal support practice, providing and using ‘Plan, Do, Study, Act’ (PDSA) cycles to review periods of leave with the patient, carer and the team. Patients’ carers were also given workbooks and videos and a full day workshop focusing on psychoeducation of eating disorders, how to support someone with an eating disorder and transition planning.

Outcome Data

Data was collected for both patients and carers at baseline, end of treatment (discharge) and three months follow-up. Questionnaires remained the same throughout except for the addition of a semi-structured interview at three month follow-up.

Comparison Cohort

We used previous audit data from the Eating Disorders Service from 2007 to 2017 to compare admission outcomes with the ECHOMANTRA cohort. Audit data was available for admission (baseline) and end of treatment. Patients were matched on their age and duration of illness to a degree of (+/- one year). 152 patients from the audit data were consecutively selected for analysis and included in the mixed effects model as a predictor variable.

Patient Quantitative measures

Patient demographic information as well as their weight and height were collected at baseline and end of treatment. Routine audit measures were used to assess psychopathology and included:
Eating Disorders Examination Questionnaire (EDEQ) (Fairburn & Beglin, 1994). A standardised, well validated measure of eating disorder psychopathology.

Work and Social Adjustment Scale (WSAS) (Mundt, Marks, Shear, & Greist, 2002). A five-item reliable measure of functioning. The participant self reports their level of impairment in each domain using a nine point likert scale with a total score of 40.

Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). A 14-item self report measure of symptoms during the past week, measuring Anxiety (HADS-A) and Depression (HADS-D) with combined score (HADS-T).

Motivation Ruler (MR) is a two-item visual analogue scale with a range from 0 to 10 assessing participants self-perceived importance to change (MR-I) and ability to change (MR-A). 10 indicating the highest level of motivation to change.

Carer Quantitative measures

Carer demographic measures were assessed, as well as self-reported psychiatric and medical history.
Depression Anxiety and Stress Scales (DASS-21) (Henry & Crawford, 2005). A 21-item self report measure which measures the severity of depression, anxiety and stress symptoms.

Eating Disorder Symptom Impact Scale (EDSIS) (Sepulveda, Whitney, Hankins, & Treasure, 2008) is a self-report measure designed to asses the impact of eating disorder symptoms on the family.

Parent Versus Anorexia Scale (PVA) (Rhodes, Baillie, Brown, & Madden, 2005). A measure designed to assess parental care giving efficacy.

The Caregiver Skills Scale (CASK) (Hibbs, Rhind, et al., 2015). A validated measure of caregiving skills taught in the New Maudsley model.

Accommodation and Enabling Scale (AESED) (Sepulveda, Kyriacou, & Treasure, 2009). A validated self-report measure of family accommodation and enabling behaviours in relation to their relative with an eating disorder.

Qualitative Measures

Around three months post discharge, participants were contacted for an opportunity to give their feedback on the ECHOMANTRA intervention. Feedback was received through a semi-structured telephone interview lasting around 30 minutes. General themes to guide the feedback were: Helpful and unhelpful aspects of the intervention, sustainability of learning, working with others and questions around specific aspects of the intervention. All telephone sessions were transcribed live using these general headings and then analysed in NVivo by an independent researcher (NVivo, 2018).

Data Analysis

Questionnaire measures from patients were used to asses changes over time using linear mixed effects models with time as the main predictor. Effect sizes (ES) were calculated using cohens *d* (Cohen, 1988) between admission and three month follow-up and were interpreted as small ($\geqslant |0.2|$), medium ($\geqslant |0.5|$) and large ($\geqslant |0.8|$). Due to a smaller sample size for carers, their questionnaires were analysed using means, standard deviations and effect sizes to highlight any improvement. Quantitative analysis was performed using R (R Core Team, 2013). Qualitative feedback was then analysed using thematic analysis in Nvivo, producing higher order themes and sub themes for patients and carers separately.

Results

Demographics

Of the 31 women who participated in ECHOMANTRA, 21 with carers, 79% were single. The median number of prior hospital admissions for patients' eating disorders was one (0-6 range). 93% of patients were on psychiatric medication during their admission. The average BMI at admission was 13.67 (SD 1.45) and at discharge was 16 (SD 1.82). Patient and control demographics are outlines in (Table 1).

Of the 21 carers that took part 70% of them lived with the respective patient prior to their admission to hospital. Eighty percent of the carers were female and 80% parents, with the remaining being close friends, siblings, partners and spouse. Carers had a median of two children, 66% were in employment and 20% had their own historical issues around weight & shape.

Table 1: Patient and Control demographics. Means (M) with Standard Deviations (SD).

Demographics	*Patients*	*n*	*M (SD)*	*Controls*	*n*	*M (SD)*
Age		31	27.0 (8.8)		152	26.6 (8.7)
BMI (Admission)		31	13.7 (1.5)		152	14.4 (1.9)
Duration of illness		30	8.7 (8.4)		138	9.7 (7.4)
Age of onset		30	18.1 (4.4)		138	16.5 (6.2)
Years of education		31	15.7 (3.1)		132	15.1 (3.2)
Lowest ever BMI		25	13.2 (1.4)		143	13.1 (1.6)

Engagement with ECHOMANTRA

We were able to engage both patients and their carers on average within four days of admission and started the intervention within 11 days of a patient being admitted. All patients and carers that consented to the ECHOMANTRA intervention completed all the components of it, as outlined in the methods.

Patient weight and Length of Stay (LoS)

We were able to obtain complete data on length of stay and weight gain (kg/week average) at discharge on all patients that completed the treatment programme (n = 29) and we obtained weight on 18 patients at three months follow-up.

The ECHOMANTRA cohort averaged a weight increase of 0.51kg per week, 0.11kg per week improvement than for the comparison cohort, who averaged 0.47kg. There was a significant positive effect of time on weight (F(49) = 45.02, p < .01) with patients on average weighing 36.95kg (SD = 5.68) on admission, 43.34kg (SD = 6.43) on discharge and 43.52kg (SD = 7.58) at three month follow-up. Length of stay for the ECHOMANTRA intervention group was 88 days (SD = 34) whereas for the comparison cohort it was 112 days (SD = 71) .

Quantitative Results

Drop-out

Not all participants completed the questionnaires at each time point (there was 16% missing data at discharge, including two patients who were still in treatment) and 42% of patients and 48% of carers failed to complete their three month follow-up assessment. The data given below is for completers. We have not used any method to impute missing data.

Patients

The results from the assessment of patients are displayed in (Table 2).

Table 2: Patient scores over time. Means (M) with Standard Deviations (SD) and the Effect Sizes (d) of the change in symptom from baseline to three-months follow-up. Eating Disorders Examination

Questionnaire (EDEQ). Work and Social Adjustment Scale (WSAS). Hospital Anxiety and Depression Scale (HADS) Anxiety (HADS-A) and Depression (HADS-D) with combined score (HADS-T). Motivational Ruler Importance (MR-I) and Ability (MR-A).

Measure	*n*	*M t1*	*n*	*M t2*	*n*	*M t3*	*d*
EDEQ	31	4.7(1.2)	26	3.7(1.2)	19	3.6(1.4)	0.90
WSAS	31	27.7(7.9)	26	24.5(7.5)	19	25(9.0)	0.33
MR-I	31	8.0(2.2)	26	8.3(1.7)	19	7.1(2.9)	0.37
MR-A	31	4.6(2.8)	26	5.0(2.5)	19	4.9(3.0)	0.11
HADS-A	31	15.2(4.0)	26	13.7(3.5)	19	13.5(2.9)	0.48
HADS-D	31	13.5(4.4)	26	9.7(4.5)	19	10.3(4.4)	0.74
HADS-T	31	28.6(7.1)	26	23.4(6.9)	19	23.8(6.2)	0.72

There was a large reduction in overall eating disorder symptomology which was maintained at three months follow-up. There was also a large reduction in depression but only a moderate reduction in anxiety. The was only a small/moderate improvement in social adjustment and negligible change in parameters of motivation.

Secondary analysis - Comparison Cohort.

When comparing the ECHOMANTRA intervention against the Comparison Cohort there were no significant differences in improvements in eating disorder psychopathology $F(198) = 1.43$, $p > .05$, or any other measure administered. This suggests that despite the shorter admission length, those that undertook the ECHOMANTRA intervention had comparable improvements to TAU, over their admission.

Carers

The results from the assessment of carers are displayed in (Table 3).

There was a moderate reduction in carer burden and small/moderate increase in carers skills and an increase in efficacy reducing AN behaviours. There was little change in distress and reducing accommodating and enabling behaviours.

Table 3: Carer scores over time. Means (M) with Standard Deviations (SD) and Effect Sizes (d) of the change in symptom from baseline to three-months follow-up. Depression Anxiety and Stress Scales (DASS-21) Eating Disorder Symptom Impact Scale (EDSIS) Parent Versus Anorexia Scale (PVA) (Rhodes

et al., 2005). Caregiver Skills Scale (CASK); Accommodation and Enabling Scale (AESED) (Sepulveda et al., 2009).

Measure	*n*	*M t1*	*n*	*M t2*	*n*	*M t3*	*d*
EDSIS	21	46.3(15.6)	17	37.8(19.7)	11	36.6(18.7)	0.6
CASK	21	347.3(101.8)	17	363.6(122.8)	11	388.5(120.9)	0.4
DASS	21	35.8(20.7)	17	38.8(28.6)	11	34.7(29.6)	0.1
PvAN	21	16.5(2.7)	17	17.2(2.7)	11	17.3(2.4)	0.3
AESED	21	51.4(27.2)	17	51.8(31.2)	11	49.7(25.3)	0.1

Qualitative Results

Thematic analysis was used to identify higher order themes and subthemes from the semistructered feedback interview from both patients and carers. Details of the higher order themes and the most common subthemes are shown in the paper.

Patient feedback on ECHOMANTRA

Intervention Acceptability

Specific elements deemed useful.. Examples given include general acceptability and engagement in intervention along with more specific feedback such as consistency, flexibility, focus, structure as well as references to specific tools or techniques.

“I think it was helpful for my recovery, I found it really useful. It was something completely different to the rest of the treatment programme which was a valuable addition. It also focused on practical skills and real-life situations that the psychology groups didn’t really touch on.”

Bridging the gap between inpatient and discharge. Refences to the benefits of the intervention to planning for transitions and discharge.

“I really liked having something that I felt I could work on that was linked to real life with a more positive focus, focused on what to do away from the ward and how to transition after discharge. I enjoyed focusing on moving forward in my recovery, I found that working towards discharge was very positive.”

Challenging Aspects of Participation

Intervention specific challenges. Joint meals, for some, were a particular problem or challenge. Some reports indicated a perceived irrelevance of intervention to current state of health or mismatch between stage of recovery and stage of treatment. This appears to be due to patient's own perceptions of what is being taught, on offer etc. and where they feel they are at in their own recovery process.

“Towards the end the booklet didn’t match where I was at in terms of my treatment. Planning meal with carer for example happened after I had already been on some home leave and had some meals with my partner. I had a planned short admission, so sometimes where I was in treatment didn’t match the booklet.”

Experience of carer participation

Positive effects of carer participation on patient. Personal and individual positive effects to either one's own recovery or on carer/patient relationship.

"I felt less guilty or like a burden after my partner had attended the workshops and done ECHOMANTRA. It was a turning point for us in my recovery, it was the first time we have been offered support as a couple and involved both of us in my treatment, we feel that this was crucial to my recovery."

Suggestions for improvement and further development

Changes to structural aspects. General suggestions for intervention development, some of which include greater flexibility, more individualised programs, goal setting placement, more home leave review sessions and more joint meals.

"More flexible and individualised with what aspects we talked about when. More integration with the whole staff team, for example bringing ECHOMANTRA materials into ward rounds.

Carer Feedback on ECHOMANTRA

Intervention Acceptability

Specific Useful aspects of the ECHOMANTRA intervention. General Acceptability of intervention includes references to materials, workshops including the interactive nature of workshops, roleplays etc., communication support and using animal models.

"I find myself thinking about the animal models a lot. Sometimes I notice myself being a certain animal, often a rhino, this helps me to notice my behaviours and actions and to change them to be more supportive. I have read all the books which has been so helpful but also having ECHOMANTRA and the workshop to go along with it really helped me to solidify this knowledge."

Carer Challenges

Post-discharge support. Post discharge difficulties, either in terms of little or no support or inadequate support from other services.

"After discharge we received less support as a family from outpatient services, only a carers support group that was more about airing stories rather than any skills or practical support."

Suggestions for Improvement

More guidance or specific changes to intervention. More guidance or suggested changes to intervention itself, in terms of specific aspects, telephone support etc.

"Perhaps some guidance around supportive messaging and phone calls and what we can do to support as friends."

Discussion

The results from this feasibility study suggest that ECHOMANTRA is an acceptable and effective intervention for improving patients transition from hospital to the community. We were able to cautiously confirm our first hypothesis as it appeared that in the context of introducing the ECHOMANTRA intervention the process of discharge was easier in that the length of stay was reduced, by almost four weeks (The caveat to this interpretation is that we cannot infer causality without a randomised controlled design). We also found that the outcomes were similar to the comparison cohort and were sustained post-discharge. We also confirmed our additional hypothesis in that we found small to moderate improvements in carer skills with less carer burden.

As this is a novel approach to transitions it is difficult to find comparative studies. Most previous studies have not jointly targeted patients and their family and/or have been delivered after discharge with longer follow-up periods. However, the finding that outcomes may be better sustained if patients are given specific help to manage the transition replicates what was found in previous studies (Fichter et al., 2012; Sternheim et al., 2017). The results are also consistent with what has been found when care is supplemented with information and skills for families such as in (CASIS) which was also set within specialised NHS eating disorder units in the UK (2007 to 2010) (Hibbs, Magill, et al., 2015). The intervention used in CASIS was an earlier prototype of the current carer intervention (ECHO). In CASIS the length of admission was also shortened, albeit not significantly, in the ECHO group. The patients in the current study were older, with a longer duration of illness (features associated with a poor prognosis). It is, therefore, not suprising that in this study carer burden (EDSIS), distress (DASS) and accommodating behaviour (AESED) was higher at baseline and across time points and possibly may explain why we failed to find an improvement in carers distress or accommodating behaviours. Another reason may be that we did not have the resource to provide personalised advice which may be needed to help reduce this maintaining behaviour in CASIS carers were offered six sessions of telephone support).

The intervention was highly valued by both patients and their carers. Previous research on patients experience of inpatient care found that one of the key themes was fear of discharge (Smith et al., 2016). The focus of this intervention was on facing these fears by moving forward with their recovery whilst taking a positive and motivational stance, appeared to be relevant and helpful. Both groups commented positively on the real life, practical and positive skills. The emphasis on developing a recovery identity, primed both patients and carers to come up with solutions to the practical and emotional barriers around reintegration with society, such as getting back to work or school and socialising with support networks. These themes have previously been suggested to be important in maintaining treatment improvements post-discharge (Cockell, Zaitsoff, & Geller, 2004) and are commonly cited as important for readjustment in other forms of psychosomatic conditions (Wolf, Chung, & Kordy, 2010). This was reflected in the feedback from patients who expressed that ECHOMANTRA's focus on discharge and transitioning successfully from the beginning, was a very positive experience.

The thematic analysis from carers described how they felt that they had been previously excluded from treatment. Social support is of great value to enable the transition from hospital back to the community, for example empathic caring relationships were identified as being essential for recovery (Pettersen & Rosenvinge, 2002). This was echoed in the carer feedback from ECHOMANTRA where it was highlighted that the skills training that taught carers different interpersonal skills, including empathic caring, helped them to change their behaviours and actions to be more supportive. This collaborative approach was appreciated by patients who expressed that their carers also receiving an intervention was a turning point in their recovery.

Limitations

There are several caveats to this optimistic summary. Patients with an adverse outcome and less motivation may have been excluded from the study, either because they failed to meet the inclusion criteria or because they excluded themselves from participation. For example, 50% of patients admitted to the service were not able to be part the study. A large portion of patients excluded were because of transfer to other hospitals for nasogastric tube feeding. Also, the improvement may be linked to temporal changes in ward functioning. There has, for example, been a steady fall in the length of stay over the last 10 years. This underlines the importance of undertaking further study with a RCT design.

Another limitation of the study was the high levels of missing data and a small carer sample. In part this is related to the high burden on carers who found it difficult to fill in questionnaires in their own time. Also, some of the measures may have not been relevant as in some cases the carer was not a parent for 20% of our cohort and/or did not live with the patient. PvAN for example is only relevant if the carer is a parent and AESED is less relevant if the carer and the patient do not live together. Future studies should consider questionnaires that consider the impact on other relationships.

Conclusions

This study has found that both the acceptability and efficiency of inpatient care for AN may be improved by augmenting treatment with support for both patients and their carers. Such an intervention is of value to help prepare patients and their carers for transition from inpatient care back to the community. Further work using a RCT design is needed to explore whether such an intervention may improve outcomes and reduce re-admission rates.

Acknowledgements

ECHOMANTRA was funded by the Health Foundations innovation for improvement scheme under GIFT code 7635 CRM 2617. JT is part funded by the National Institute for Health Research (NIHR) Mental Health Biomedical Research Centre at South London and Maudsley NHS Foundation Trust and King's College London. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health. We would also like to acknowledge the help from Ms Lynn StLouis and Mrs Zoe Vazquez-Sanchez for their management and help recruiting for the project. Finally, we would like to thank all the patients, carers and staff at the Bethlem Royal Hospital who helped us with this study.

Conflicts of interest

JT is an author on the carer manual used in the study. The other authors declare no conflicts of interest.

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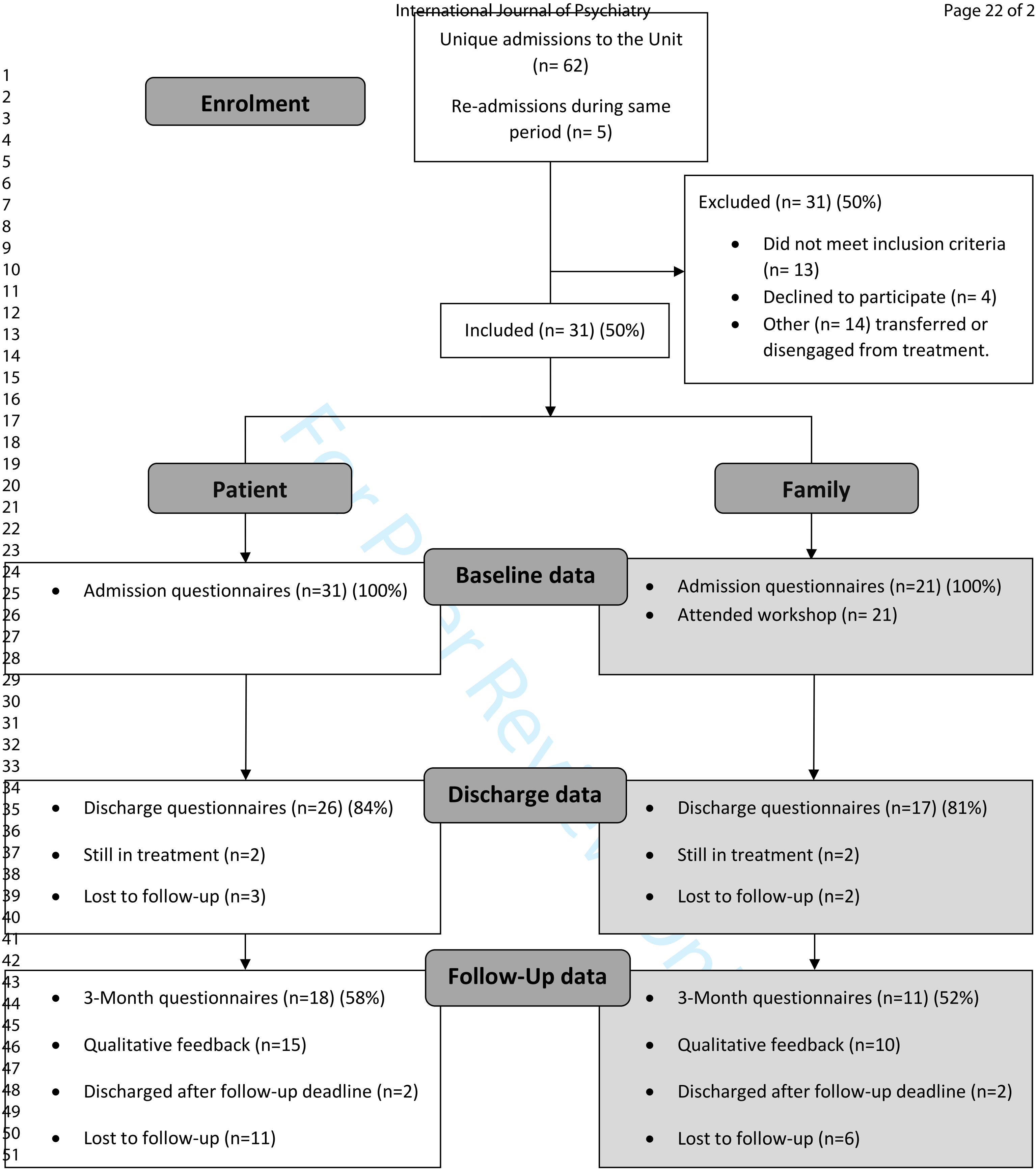

Figure 1: ECHOMANTRA recruitment consort flow diagram 09.01.2017-25.01.2018.