

A Qualitative Evaluation of Adolescent Patient's and their Caregiver's Perspectives following a Skills Intervention for Caregivers of People with Anorexia Nervosa

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Abstract

Objective: Caregivers request information; guidance and support in helping their loved one recover from Anorexia Nervosa (AN). The question is whether skills training interventions are of help, both to them, and indirectly for the person with AN. The aim of this study is to examine feedback from adolescent patients and their caregivers about their experiences following a skills intervention which compared two forms of interventions for caregivers (skills training materials, with or without coaching {E}) with Treatment As Usual (TAU).

Method: Patients and caregivers from 38 eating disorder outpatient centers were randomized into one of three groups: a) skills training materials + TAU, b) skills training materials plus telephone coaching + TAU) or c) TAU alone. Feedback forms were sent to participants at 12 months and completed by 69 patients (n=26E; n=21 EC; n=21T) and 144 caregivers (n=50E; n=47EC; n=47T). Data were coded blind to treatment group by two researchers using thematic analysis.

Results: Caregivers and patients recognize more positive changes in their caregivers' approach than those in TAU. The additional coaching element was associated with a greater level of perceived self-changes in carers, e.g. relationship improvements, reduced anxiety, anger and hostility, than self-help alone and this, in turn, was greater than in TAU.

Discussion: Qualitative feedback suggests that skills training materials may produce changes in caregiver behaviour, noted by patients and caregivers, particularly in the more intensive intervention group. Statistical analyses should be employed to explore these results further. This approach is easily disseminated and may play an important role in breaking some of the barriers to early intervention in this patient group.

Keywords: Eating disorders; Anorexia nervosa; Carer skills training interventions

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Introduction

Anorexia nervosa (AN) is a severe psychiatric illness typically developing at age 16 (Micali et al., 2013) [1]. Guidelines from the National Institute for Clinical Excellence recommend that most people with AN be managed on an outpatient basis (National Institute for Clinical Excellence, 2004) [2]. This means that family members are often involved in the management of the illness

and frequently find themselves facing a wide range of emotional and behavioural turmoil on a daily basis. Two systematic reviews, however, have found that carers themselves find their role burdensome and distressing (Anastasiadou et al., 2014; Zabala et al., 2009) [3, 4] and frequently report that they lack the information, guidance and support as to how best to address the symptoms (Haigh & Treasure, 2003) [5]. A recent qualitative study also provides rich data exemplifying the stress mothers

experience when their adolescent daughters have AN (Bezance & Holliday, 2014) [6]. Caregivers express a need for support both from professionals and other parents (Bezance & Holliday, 2014; Roots et al., 2009) [6, 7]. We have developed skills training materials (Experienced Caregivers Helping Others (ECHO)) for sharing skills and knowledge for caregivers (lay and professional).

The "Experienced Caregivers Helping Others (ECHO)" intervention is based on the cognitive interpersonal maintenance model of AN, and aims to help caregivers focus their own strengths and resources by using effective change strategies. The resources teach communication, fear extinction and behaviour change skills (Cairns et al., 2007; Goddard et al., 2011; Grover et al., 2011; Hildebrandt et al., 2014; Pepin & King, 2013; Rhind et al., 2014; Sepulveda et al., 2009; Treasure et al., 2008) [8-15]. An additional component of this model addresses emotionally driven behaviours such as criticism, hostility, overprotection, accommodation and enabling behaviours that can be elicited because of the difficulty of coping with AN symptoms (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013) [16, 17]. These are modifiable behaviours and caregivers may benefit from skills training to reduce those (Rhind et al., 2014) [13]. Caregivers are encouraged to reflect on their responses to the illness and to build awareness of how they can adapt their behaviour to have a positive effect on the trajectory of the illness. Additionally, they are taught to be role models to the person they are caring for and encouraged to engage in self-care, adaptive coping and emotional intelligence (Macdonald et al., 2014) [18].

A recent meta-analysis of interventions for caregivers found a moderate-sized reduction in caregiver burden, distress and the ECHO intervention reduced expressed emotion and accommodating and enabling behaviours (Hibbs et al., 2015b) [19]. Moreover, in a study where the ECHO intervention was added to the inpatient treatment of adults with severe enduring AN, the patients identified positive caregiver behaviour changes (Macdonald et al., 2014) [18] and also showed improved symptomatology and quality of life at six months along with reduced bed use (Hibbs et al., 2015b) [19].

This current study is a qualitative evaluation to examine feedback about the use of the ECHO intervention in families of adolescents. A published protocol provides a detailed account of the intervention and the study design (Rhind et al., 2014) [13]. The aim of the study is to examine the experiential perspective from caregivers and their adolescent loved ones of having participated in a career skills training intervention, particularly in terms of perceived behaviour change in both patient and caregiver.

Methods

Participants (n=149 patient/caregiver dyads) were part of a pragmatic three-arm multi-centre parallel group pilot randomized controlled trial (Rhind et al., 2014) [13]. Consenting caregivers of patients who met the eligibility criteria were randomly allocated to receive ECHO (E) (book and DVDs) in addition to TAU, ECHO-C (EC), (book, DVDs and ten 30-40 minute telephone coaching sessions in addition to TAU, or TAU alone). The sample included caregivers and their adolescents (age 13-21 years) with AN or ED

not otherwise specified AN type (EDNOS-AN) according to the DSM-IV criteria (American Psychiatric Association, 1994) [20], recruited from 38 eating disorder outpatient services across the United Kingdom (UK). The ECHO materials and coaching were delivered from the research hub. There was no further interaction between the research center and the contributing clinical sites where usual care was delivered. Follow-up assessments included computerised self-report instruments and structured interviews for both parents and patients. Main ethics approval was granted by the Northwick Park Hospitals Ethics Committee (11/H0725/4). Site specific ethics and governance approval was granted on all participating sites and this study was adopted by the Clinical Research Network (CRN).

Inclusion criteria required at least one caregiver (typically parent/s) to participate. Caregivers were required to be identified by the patient as 'carer', to be currently living with the patient with the intention of living together for the following year. Other close caregivers were also encouraged to take part. "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. Patient demographics are presented in **(Table 1)**. A full description of methodology that includes a detailed account of Participants, Intervention and Study Design appears in (Rhind et al., 2014) [13].

Qualitative feedback was ascertained at 12 months from randomization. From the 149 patient/caregiver units, feedback questionnaires were completed by 69 patients (n=26 E; n=22 EC; n=21 TAU) and 144 caregivers (n=50 E; n=47 EC; n=47 TAU). The process evaluation questionnaires have been used in previous studies of eating disorders (Gowers et al., 2002) [21] and contained questions that related to their experience of the study and either a) their caring experience (caregivers) or b) their experience of caregiver support (patients). Patient forms asked 1) for their experience in taking part in the ECHO project and 2) their perspectives of their caregiver's role and any changes over the past year, particularly in the period following their first assessment with the outpatient eating disorders team. Meanwhile, caregivers were asked to share their experience as a caregiver of someone who has received outpatient care for AN in term of how they have reacted, coped with and managed the situation, pre and post intervention. Copies of the feedback forms are available from the first author.

Analysis

A thematic framework approach was adopted in the analysis of the written narratives on the feedback forms. Thematic analysis is a qualitative method for identifying, analyzing and reporting patterns or themes within a dataset (Braun & Clarke, 2006) [22]. Two researchers (PM and KB) worked independently on the identification of themes. An 'utterance' was coded and placed in a sub-theme; when the participant changed topic, this would constitute a new utterance and sub-theme. Researcher 1 (PM) worked on the entire dataset whilst Researcher 2 (KB) worked on a sub-section (10%) within. Feedback forms were read several times and initial codes generated and incorporated into meaningful clusters before being entered into the computer software programme (Nvivo Computer Software, 1999) [23].

Table 1 Patient characteristics by treatment group.

	ECHO-C n= 21	ECHO n= 26	TAU n= 21
<i>Demographics</i>			
Age (years)	16.35 (2.02)	16.66 (1.98)	17.21 (2.24)
Female	19 (90.5%)	24 (92.3%)	19 (90.5%)
Ethnic Origin			
White	21 (100%)	24 (92.3%)	19 (90.5%)
Asian/Black/mixed	0 (0%)	2 (7.7%)	2 (9.5%)
Education			
No Qualification	7 (33.3%)	13 (50%)	8 (38.1%)
O- level / GCSE	7 (33.3%)	6 (23.1%)	8 (38.1%)
A-level	6 (28.6%)	6 (23.1%)	3 (14.3%)
University/higher degrees	0 (0%)	0 (0%)	1 (4.8%)
Other	1 (4.8%)	0 (0%)	0 (0%)
Missing	0 (0%)	1 (3.8%)	1 (4.8%)
Patient living with caregiver	20 (95.2%)	26 (100%)	19 (90.5%)
Patient face-face contact with caregiver p/ week			
0-7 hours	2 (9.5%)	0 (0%)	1 (4.8%)
8-14 hours	2 (9.5%)	1 (3.8%)	3 (14.3%)
15-21 hours	2 (9.5%)	6 (23.1%)	2 (9.5%)
>21 hours	14 (66.7%)	19 (73.1%)	14 (66.7%)
<i>Clinical characteristics</i>			
Duration of illness (months)	23.95 (21.00)	24.31 (28.56)	27.62 (26.25)
Lowest lifetime BMI	16.05 (2.14)	16.25 (2.08)	14.94 (1.63)
No. previous hospital admissions			
0	14 (66.7%)	19 (73.1%)	14 (66.7%)
1	5 (23.8%)	4 (15.4%)	3 (14.3%)
2	2 (9.5%)	3 (11.5%)	3 (14.3%)
3 or more	0 (0%)	0 (0%)	1 (14.3%)

In devising a final thematic framework, discussions took place between the two researchers on six occasions (4 x caregivers at $n=20$, $n=81$, $n=115$, $n=144$ and 3 x patients at $n=10$, $n=28$, $n=68$) via skype, email and face to face. Coding procedures were discussed, coding practices assessed and agreement obtained on emerging frameworks. After each discussion, themes were either consolidated or merged into existing themes. Descriptive labels were altered to better reflect the subject matter or deleted, if deemed irrelevant to research aims. Both researchers were blind to group allocation and blinding was only lifted a) once agreement had been made with regard to final thematic framework and b) upon agreement that data saturation had been achieved.

Results

Five main themes emerged from both patient and caregiver data sets. These are depicted in **Table 2** (caregivers) and **Table 3** (patients). In order to preserve anonymity, any personal references to either caregiver or patient in the quotations that follow are represented by the letter 'A'.

Caregiver themes

Superordinate themes for caregivers included: 1) Perceived self-change, 2) Caregiver and patient efficacy, 3) Challenges, 4) Coping mechanisms and 5) Service provision and caregiver guidance (**Table 2**).

Perceived self-change

Carers spoke of improvements in relationship and communication, in particular, any change(s) noticed by carers with regards to their own attitudes, behaviour or approach to the AN and patient, as well as perceived improved relationships and communication with the sufferer. There appeared to be a greater number of reports in the EC group than in E alone or TAU (E: 34%; EC: 51%; TAU: 32%). Carers also reported *reduced anxiety, anger and hostility* in terms of a greater sense of calmness and less maladaptive emotions, e.g. guilt, anger and hostility. Again, there seemed to be a greater percentage of these reports in the EC group (E: 22%; EC: 36%; TAU: 11%).

I think we have a close and good relationship. She is able to talk to me about her anxieties. We have learnt to do this in the past year. I have been able to give her time and space. (EC)

Learning that a calmer more measured approach works better. When she is angry be non- confrontational and take a step back (E)

There were also reports of *increased awareness and understanding of AN* across all groups, particularly in E, (E: 44%; EC: 28%; TAU: 30%), as well as the need to *promote greater independence*, i.e. reports of carers having stepped back whilst recognizing the importance of the patient being more responsible for his/her own

wellbeing. There were a greater incidence of *promoting greater independence* amongst the EC participants (E: 12%; EC: 23%; TAU: 11%).

My understanding and knowledge has been increased by attending appointments with experts. We have learnt so much how to encourage and support someone with an eating disorder. (TAU)

I have had to learn to support in a way that shows her that I trust her to make decisions/mistakes and manage the ED herself and not 'police' her. (EC)

Twenty four carers also reported increased emotional intelligence over the last year, in terms of inner strength and mindfulness, i.e. looking after one's own emotional and physical wellbeing (E: 22%; EC: 15%; TAU: 13%), whilst 21 carers reported increased compassion, tolerance, kindness and patience. Interestingly, in the latter, these appeared with greater frequency in TAU (E: 12%; EC: 6%; TAU: 26%).

I know I have to protect myself (near the oxygen mask) to be of any good to A. I need to be centered/positive (E)

I am a lot more patient as a result of my sister's illness. (TAU)

Twelve participants reported *no change* in their behaviour or approach to the illness over the course of last year, i.e. during and after intervention.

Caregiver and patient efficacy

There were some interesting observations within this superordinate theme. *Use of helpful strategies and techniques*, for example, included many of the skills taught in the intervention materials, such as communication techniques, calmness, openness and honesty, passing more responsibility to sufferer for wellbeing, bigger picture thinking and challenging comfort zones. It was interesting to note that although many of the skills and techniques referred to are taught in the New Maudsley approach, references to the skills appeared in the narratives of all three groups, including TAU which might suggest a "contamination" effect in TAU (E: 24%; EC: 43%; TAU: 36%). The following three quotes, for example, were all written by caregivers in TAU and one quote in particular appears to imply previous training in caregiver skills.

Communicating without conflict and accusation (from workshops done) and understanding that some behaviours are normal when dealing with anorexia. (TAU)

Externalizing eating disorder, not getting drawn into discussions on food. Sticking rigidly to food plan. (TAU)

Remember that the moods (outbursts) are the disorder and not daughter. Listen to her feelings and try to discuss worries. (TAU)

The sub-theme '*healthy functioning (patient)*' contained the researchers' interpretations of narratives that indicated normalized eating behaviours and the patient engaging in normal life with regards to school, social life and healthier eating behaviour. Although in some cases, narratives contained some signs of AN behaviours present, in general, feedback indicated a normal age related lifestyle with little support required from

caregivers or professionals. There was a higher incidence of these reports in the intervention groups (E: 38%; EC: 30%; TAU: 19%). Although one should exercise caution in directly attributing any change to intervention effects, questions posed in the feedback forms did relate to changes 'during the past year', i.e. between the pre and post intervention periods.

He's doing really, really well. Working towards recovery. Doing well at university, come on a lot in the past year, gone for an interview for a job today, lots more confidence. (E)

Coping well. Eating normally, still on anti-depressants but free in the main from crippling anxiety – hoorah! (EC)

Over 40% ($n=65$) of the sample reported sharing a *positive relationship* with their loved one, despite the challenges of living alongside AN. Carers also reported providing *emotional support*, (encouragement, guidance, compassion) and *practical support* (mealtime support, financial support, transportation, food shopping, shared goal setting and problem solving strategies) with a slightly higher incidence of emotional support being reported in the guided self-help group (E: 42%; EC: 51%; TAU: 40%).

Being there for her, not being judgmental. Gently persuading her to eat. Reminding her that she is loved by so many people and that her friends adore her. (EC) ...

Had to keep a diary for his eating...had to eat with him at a set time, made sure he had his breakfast, lunch and tea put in front of him ... (E)

Caregivers across the sample also reported an awareness of *caregiver impact*, with narratives reflecting on the consequences and influence of one's own actions on the trajectory of the illness.

You have to be so careful about saying the right thing. The person affected is in such a vulnerable place in their lives that you do need to filter what you say, particularly regarding the disorder. (TAU)

Caregiver challenges

Sixty nine percent of caregivers ($n=99$) described *the negative impact on self and/or family* of living alongside AN. Narratives included reports of helplessness, frustration, high anxiety, hostility, conflict, anger, guilt, exhaustion and fear, as well as disruptions to family life in general. There were several reports of marital and relationship discord, feelings of isolation and concern for siblings, as well as detrimental consequences on one's own mental and physical health.

Particularly hard on brother and sister. They found it difficult to be at home (both living away from home). Sister particularly found it more stressful – unsure what to say to her. She also felt uncomfortable around her – body image, weight issues. She felt A was 'judging' her/ comparing herself with her. (E)

Marriage breakdown....trying to maintain stable home life for myself, A and son. (EC)

There have been months where I have been powerless to stop/slow down A's decline. It has been terrifying. Our worst year. I have felt alone and overwhelmed. Useless. (T)

Practical burden of continuous care, i.e. balancing the demands of care with other life commitments, including financial burden, was reported by almost a third of the sample. Likewise, *problematic and comorbid behaviours*, reflected the existence of continued AN behaviours, denial, maladaptive thoughts and emotional turmoil along with refusal to engage in therapy, exclusion of caregivers in any form of attempted support, scant participation in healthy life activities, i.e. little improvement in eating or other comorbid behaviours.

We have had to call the police and paramedics twice because she became uncontrollable and they had to restrain her. We had also had to deal with A self-harming or attempting to self-harm. (EC)

Twenty nine percent of the carers ($n=42$) referred to the protracted course of the illness whilst 21% of the sample ($n=31$) wrote of their *doubts, uncertainties and trust issues*, including self-doubt in their own ability as 'caregiver', along with fear for the future and continuous struggles to understand the illness, their caring role and its impact.

She is coping in a calmer manner with her situation with less extreme behaviours. Her weight is now stable but she still becomes distressed by this. Her aim is to be back at school full time and she is making progress with this although sometimes with difficulty. (EC)

Fears even when things are OK that we're missing something and it won't be OK for long. (TAU)

Weaker sub-themes included *relationship problems and difficulties*, carers feeling they had *no impact whatsoever* on their loved one's mindset and behaviour, *resignation and hopelessness* and *sibling challenges*.

I don't think I have an impact on A, she is her own person, an adult as she keeps reminding me. (E)

Coping Mechanisms

The data generated interesting findings on carer coping mechanisms; the most widely reported being *social support* and *work, hobbies and non-eating disorder interests*.

I gain support from my daughters, siblings and sometimes (more so latterly) from my partner – her father. (EC)

I have kept working which has helped me enormously to continue to have a life outside of the home. (TAU)

Other coping mechanisms included *positive mindset and self-soothing strategies* (the use of emotional intelligence and positive thinking strategies), *education* (reading of literature, surfing the web, active searching for information on EDs and mental illness), *medication, alcohol and own eating problems* used to dull emotional pain and *spirituality* (the use of prayer or one's faith as a coping strategy).

It's been hard to watch her at her lowest psychological point, but I've always tried to stay positive. (TAU)

Part of my coping strategy has definitely involved alcohol, I am afraid to say. Some evenings involve several glasses of wine to blank out the past and to induce sleep. Not a great solution, I

admit, but unfortunately the truth. (E)

Most helpful is the internet – reading about anorexia, research evidence. (EC)

Service provision and caregiver guidance

Sub-themes within the final superordinate theme include aspects of service provision, i.e. support from Eating Disorder Units, General Practitioners as well as independent support groups, research projects or individual counselling received. Forty-three percent ($n=62$) of the caregivers described *positive collaboration and experience with the treatment team* (E: 40%; EC: 49%; TAU: 40%).

The impact of outpatient care was huge. I was terribly worried about A and great relief knowing that we could get help. The regular meetings and advice helped greatly. There was an orderliness about the routine, step by step advancement to getting A to a better place. (EC)

Just under a third of participants, spread evenly across the groups, reported some form of *caregiver support and education*, such as attending counseling, therapy, caregiver training, caregiver support groups. In some cases, this was offered through the service provider whilst others sought guidance independently.

We felt empowered to help by the support group and the strategies they gave us worked for our daughter. Thank you to all the team. (TAU)

Twenty eight percent ($n=40$) of the sample made reference in some form or other to the current study. Narratives related to the DVDs and/or book, or indeed, disappointment at not having received support.

I would have loved some support! As I was on the 'no help' strand of the study I can only hope it is better for stress. (TAU)

A quarter of the sample (E: 22%; EC: 21%; TAU: 30%) expressed dissatisfaction with *the treatment, team or the system*, either from the patient or caregiver's perspective. Examples include criticism of treatment given, or aspects of the team itself, non-adherence to care or personal frustration over lack of knowledge.

I find the argument of confidentiality difficult, one day we have a level of communication, the next it changes, despite people talking about a collaborative approach and my daughter expressing that she is happy for there to be open communication. (TAU)

The final two sub-themes were *caregiver reflections* over the illness or caring role, in general. There were also accounts of having received *no support whatsoever* (E: 24%; EC: 9%; TAU: 30%).

Getting back to normal after the very little support we received became absolutely none. (TAU) (Table 2).

Patient Themes

Superordinate themes for patients included: 1) Perceived changes in caregiver(s) 2) Helpful factors towards recovery 3) Unhelpful caregiver behaviours 4) Experiential perspective of study participation and 5) Relationship with caregivers (Table 3).

Table 2 Caregivers Themes – Total $n = 44$ ($n = 50E$; $n = 47EC$; $n = 47TAU$).

	Caregivers (<i>n</i>) ^a					
	ECHO		ECHO-C		TAU	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Perceived self-change						
Improvements in relationship & communication	17	34	24	51	15	32
Increased awareness, coping & understanding	22	44	13	28	14	30
Reduced anxiety, anger, guilt & hostility	11	22	17	36	5	11
Mindfulness and self-nurturing behaviours	11	22	7	15	6	13
Promoting independence & responsibility	6	12	11	23	5	11
Increased compassion & tolerance	6	12	3	6	12	26
No change	3	6	5	11	4	9
Caregiver and patient efficacy						
Positive relationship	26	52	17	36	22	47
Emotional support	21	42	24	51	19	40
Perceived caregiver impact	21	42	20	43	22	47
Practical support	23	46	20	43	19	40
Use of helpful strategies & techniques	12	24	20	43	17	36
Healthy functioning (patient)	19	38	14	30	9	19
Role differentiation	4	8	8	17	3	6
Little or reduced involvement	6	12	5	11	2	4
Challenges						
Negative impact on self and/or family	38	76	29	62	32	68
Practical burden of continuous care	15	30	18	38	13	28
Problematic & comorbid behaviours	17	34	12	26	15	32
Slower recovery process	17	34	13	28	12	26
Doubt, uncertainty & trust issues	10	20	9	19	12	26
Relationship problems & difficulties	5	10	7	15	7	15
No impact	5	10	3	6	2	4
Resignation & hopelessness	1	2	4	9	4	9

Sibling challenges	2	4	0	0	1	2
Coping mechanisms						
Social support	23	46	28	60	24	51
Work, hobbies & non eating disorder interests	14	28	13	28	12	26
Positive mindset & self-soothing strategies	8	16	5	11	6	13
Medication, alcohol, own eating problems	7	14	4	9	4	9
Education	5	10	4	9	4	9
Spirituality	3	6	0	0	1	2
Service provision and carer guidance						
Positive collaboration & experience with services	20	40	23	49	19	40
Caregiver support and education	13	26	16	34	16	34
Support from current study	6	12	29	62	5	11
Problems with treatment, team and/or system	11	22	10	21	14	30
No support	12	24	4	9	14	30
Caregiver reflections	5	10	6	13	3	6
ECHO, Experienced Caregivers Helping Others ECHO-C, Experienced Caregivers Helping Other-Coaching; TAU, Treatment as Usual *represents the number of participants who report experiences that belong to that particular sub-theme						

Perceived change in caregiver(s)

These narratives represented patient perceptions of any changes they had noticed in their caregiver(s) over the course of the last year, i.e. pre and post intervention periods. Forty five patients reported greater insight and confidence in their carers, the ability to challenge problematic behaviours as well as improved understanding and awareness with suggestions of improved coping and coping strategies. Reports of *greater understanding, awareness and coping* were more frequent in the intervention groups (E: 73%; EC: 76% and TAU: 48%).

My Mum (primary carer) has a very good understanding of the illness. This has improved immensely since being involved with this study. (EC)

There were also reports of *improved relationship and communication* in terms of less distance, more openness and honesty in relationships and greater shared participation in non-eating disorder communication and activities. Again, narratives appeared more in the intervention groups with the greatest frequency occurring in E (E: 42%; EC: 29%; TAU: 19%). Twenty participants reported a *calmer behavioural and emotional climate* in terms of calmer family dynamics, i.e. less anger, stress and anxiety along with increased patience in their carers. Likewise, these reports occurred more regularly in the intervention groups

(E: 35%; EC: 33%; TAU: 19%).

She now talks to me about her concerns and worries involving my illness. More honest and open and is more understanding and less judgmental. All this means that she is able to know what support I need (emotionally or otherwise) (EC)

My Mum also remains a lot calmer now, as she seems to feel less responsible for my eating. Previously my Mum had a tendency to overreact at the least thing – she seems to have this more under control now. (E)

Interestingly, feedback also highlighted contamination effects, in that some caregivers in TAU group appeared to have had access to the New Maudsley materials.

She has done a lot of reading around the disorder too, including several of Janet Treasure's books and those released by the Maudsley. Over the past year, she has identified (more so than I) that perhaps many of my most rigid habits around food are less induced by AN but instead by OCD and ASD. (TAU)

Helpful factors towards recovery

Patients offered a wide range of factors they deemed helpful in the recovery process. Over half the patients, for example, listed open and non-judgmental *communication and honesty* with

the use of listening and questioning strategies as an important contributor to the recovery process.

Talking and listening to each other in a calm, open manner is very helpful. (EC)

Monitoring of meals and food intake in terms of preparation, buying food and meal support was also considered important to recovery.

Having my dinner ready when I get home from school so I cannot binge and monitoring me after dinner to make sure I am not sick. (E)

Motivational support, i.e. awareness, understanding, praise and encouragement and distractions and normality, including bigger picture thinking, non-eating disorder talk and activities were regarded important by a quarter of the sample.

She has never become angry or irritated which has been very helpful and has always been understanding and patient which has made my life easier. (EC)

Distractions and normality, i.e. bigger picture thinking, including participation in non-eating disorder activities and conversation were thought to be helpful by almost a quarter of the sample.

I find it helpful when we talk normally and when we make meal times normal so they don't seem like a big deal. (E)

Unhelpful caregiver behaviours

High expressed emotion was the most commonly quoted factor impeding recovery. Anger, anxiety, blame, stress, hostility and criticism is cited by 40% ($n=27$) of the sample. This factor appeared more frequently in the narratives in the intervention groups (E: 46%; EC: 43%; TAU: 29%). It is interesting that there was a higher frequency of E and EC patients' observations of a *calmer behavioural and emotional climate* in 'Perceived change in caregiver'. This may be further indicative of a certain element of change having occurred. *Weak boundaries and accommodating to symptoms* were also deemed unhelpful by a third of the sample.

However, my mum does not know how to handle it when I refuse to eat and gets easily frustrated, angry and upset. I do not find this helpful – it makes it more difficult for me. (E)

Aggression is not helpful their frustration and them trying to make me just deal with situations they throw on me without thinking how this may dislodge my current progress. (TAU)

She even buys food from multiple different shops so that she can guarantee I'll eat. (EC)

Lack of physical or emotional presence and communication problems were also regarded as unhelpful. Caregivers at work or living away from home allowed the patient to lapse into problematic behaviours. Lack of emotional presence, e.g. neglecting behaviours due to other life commitments was also difficult for the patient. This are links here to *communication problems* and misunderstandings, lack of understanding or parents ignoring behaviours in a bid to keep the peace.

They did not let it thrive although if they were busy I had the

opportunity to play into the hands of the illness without them realizing. (E)

Persistent questioning or assumptions that I will "go and have a carrot" are not helpful. (TAU)

The remaining factors patients report as detrimental to recovery include *food, weight and shape issues and talk, lack of understanding, intrusiveness and control, disclosure of illness to others* and one patient describes her caregiver's own eating and food issues as unhelpful.

When negative comments are made about their shape or others' shape, makes me question my own more. (E)

I sometimes found that the more rules and barriers my Mum tried to implement, the more determined my eating disorder would be to fight against them. Particularly if our arguments became very verbal, the stubbornness of my eating disorder would thrive. (EC)

She is often dieting and discussing with me her body hatred. She told me I looked lovely when very ill which I misinterpreted. (TAU)

Experiential perspective of study participation

Seventy eight percent of participants ($n=53$) reported positive aspects of having taken part in the study (E: 92%; EC: 81%; TAU: 57%). Narratives reflect appreciation, acceptability and positive impact of study, i.e. acceptability of questionnaires and monthly telephone calls, or a general feeling of the project having helped their situation or that of their caregiver by enhancing self-reflection.

The extra information has been brilliant. Giving my carers the information they needed to cope and to support me through the illness. (E)

Meanwhile, a similar proportion of the sample, 75%, ($n=51$) reported negative aspects of participation in terms of problems with telephone calls, difficulties encountered in completing questionnaires and of the study having had a negative impact on either self or caregiver. Examples included the emotional impact of being reminded of AN symptoms in the maintenance period, or the feeling of having been duped into participating and not receiving any help (TAU). There was also some confusion, particularly after outpatient treatment had ended, as to what period of time the questions referred.

Felt that myself and my parents had been 'conned' by my ED nurse into participating, We thought we would be getting help and advice but ended up being the group that got nothing. (TAU)

If completely honest, I didn't have any positive experience from this project. As I recovered very quickly the project was completely out of sync with my personal recovery and should have been kept alongside each person's personal recovery time, rather than using an 'average' recovery sign. (E)

To be honest I didn't get anything out of this. There was nothing really there to help me – it was just questionnaires (EC).

Thirty nine patients felt that the intervention had no perceivable effects on either themselves or their carers. Interestingly, there

Table 3 Patient themes - Total n = 68 (n=26E; n=21EC; n=21TAU).

	Patients (n)*					
	ECHO		ECHO-C		TAU	
	n	%	n	%	n	%
PERCEIVED CHANGES IN CAREGIVER(S)						
Greater understanding, awareness & coping	19	73	16	76	10	48
Improved relationship & communication	11	42	6	29	4	19
Calmer behavioural & emotional climate	9	35	7	33	4	19
Greater independence & trust	1	4	2	10	2	10
Negative changes	1	4	0	0	1	5
Helpful factors towards recovery						
Adaptive communication & honesty	11	42	11	52	13	62
Monitoring of meals & food intake	9	35	10	48	7	33
Motivational support	8	31	3	14	7	33
Distractions & normality	9	35	4	19	3	14
Challenging behaviours & boundary setting	2	8	2	10	7	33
Calmer emotional climate	3	12	3	14	2	10
Independence & responsibility	4	15	2	10	1	5
Professional help	4	15	1	5	0	0
Concern for caregivers	0	0	1	5	1	5
Role modelling	0	0	0	0	1	5
Unhelpful caregiver behaviours						
High emotion	12	46	9	43	6	29
Weak boundaries & accommodating symptoms	7	27	7	33	8	38
Lack of physical or emotional presence	9	35	1	5	4	19
Communication problems	3	12	5	24	5	24
Food, weight & shape issues/talk	6	23	1	5	2	10
Lack of understanding	5	19	2	10	2	10
Intrusiveness & control	2	8	3	14	2	10
Disclosure of illness to others	2	8	2	10	1	5
Caregivers' own eating & food issues	0	0	0	0	1	5
Experiential perspective of study participation						
Positives	24	92	17	81	12	57
Negatives	20	77	17	81	14	67
No effect on self or caregiver	19	73	9	43	11	52
Altruism	9	35	11	52	5	24
Uncertainty over study aims & methodology	1	4	4	19	1	5
Relationship with caregivers						
Appreciation of caregiver impact & support	18	69	14	67	18	86
Close relationship	13	50	15	71	15	71
Problematic aspects of relationship	15	58	10	48	8	38
Guilt, empathy & awareness of carer struggles	9	35	7	33	6	29
Constructive caregiver coping approach	3	12	3	14	3	14
ECHO, Experienced Caregivers Helping Others ECHO-C, Experienced Caregivers Helping Other-Coaching TAU, Treatment as Usual *represents the number of participants who report experiences that belong to that particular sub-theme						

was a higher percentage of patients in E who reported no particular intervention effects (E: 73%; EC: 43%; TAU: 52%).

It hasn't changed I don't think – carer #1 is none the wiser as that is how she deals with things. Carer #2 did his own research and didn't really have anything to do with this project. (E)

Meanwhile, 25 out of the 68 patients gave altruistic reasons for

participation. Many cited feeling a sense of 'giving back' and the desire to help others. These reports occurred with greater frequency in the intervention groups, particularly in the EC group (E: 35%; EC: 52%; TAU: 24%).

I felt encouraged that I was able to be useful in some way and contribute towards a programme designed to improve the lives of carers and those suffering with an eating disorder. (EC)

Relationship with caregivers

The final superordinate theme contained sub-themes referring to relational aspects. Seventy three percent of patients ($n=50$) expressed an *appreciation of caregiver impact, support and understanding* in the manner they approach and deal with the illness. They reported caregiver coping strategies and appreciation of constant support. Sixty six percent of the sample ($n=45$) also reported aspects of a *close relationship* with their caregiver.

Even though I shield them from the ED and my low moods as much as possible, it is highly beneficial to know that they are there and that their love, care and support is ongoing and unconditional. Without such support, I would have no defense against the ED onslaught and would simply bow down to it. (TAU)

However, almost half the sample also ($n=33$) reported *problematic aspects of the relationship* to varying degrees, which is understandable given the stressful conditions of living alongside AN. Narratives indicated a lack of understanding, problematic caregiver coping, caregiver anxiety and belittling of the illness.

The expectation for them of recovery is for me to like who I am and whatever I look like. My mum especially believes that people in the healthy weight range do not have such intrusive thoughts – she doesn't understand that mental illness cannot be fixed by weight gain. (TAU)

There were also some suggestions of patients experiencing feelings of *guilt, empathy and awareness of caregivers' struggles* ($n=22$; 32%). Guilt is often particularly pronounced when the patient recognizes the impact of their illness on their caregiver's own mental or physical wellbeing.

I think mum finds it hard always trying to keep the peace. She now has high blood pressure and diabetes.... I worry that my anorexia has been detrimental on her health. Dad struggles to cope with and understand the anorexia. (EC)

Discussion

This current study is a qualitative evaluation to examine feedback about the use of a caregiver skills training intervention in families with adolescents with AN. The Medical Research Council's criteria in terms of development and evaluation of an intervention considers a) the practical effectiveness of the intervention (does it work) and b) what are the active ingredients and how are they exerting their effect (how it works). This study, then, considers the second criterion by offering a greater insight into the nature of both patients' and carers' needs and experiential perspectives of having taken part in a skills training intervention. Quantitative analyses have been conducted in tandem with the qualitative element (Peynenburg et al., 2015; Rhind et al., 2015) [24, 25]. It is hoped that both approaches will provide a sense of complementarity, where different methods are used to assess different components. The current study examined the experiential perspectives in narratives from both patients and their caregivers after having taken part in a carer skills training intervention, particularly in light of any perceived changes reported during the post intervention period.

Caregivers

The additional coaching element was associated with a greater level of perceived self-changes, e.g. relationship improvements, reduced anxiety, anger and hostility, promoting independence and responsibility than self-help alone and this, in turn, was greater than in Treatment As Usual. Overall, there was very little feedback that suggested that the intervention was irrelevant or inappropriate for this patient group. Indeed, some caregivers said that the information would have been helpful at an even earlier stage. This is interesting as we thought that we were ascertaining patients early in their illness. Previous work has found that mothers find being given skills and practical advice helpful early in the illness (Bezance & Holliday, 2014) [4]. It is also important to consider those caregivers' recommendations that guidance and support be given upon diagnosis and introduced at the outset of the illness. There can be a long interval between when the first symptoms develop; acknowledgment that help and accessing expert help is needed (12 months) (B-EAT, 2015) [26]. A German study also found that the duration of untreated illness in the early onset group was high (Neubauer et al., 2014) [27]. One should bear in mind the costs of such delays and the ramifications on caregivers' (and siblings') family and social lives. There are implications in areas of work, extra financial burden and the family members' own physical and mental health. Delays can also carry heavy costs for their loved one's welfare in terms of emotional and physical wellbeing, education and social development and a poorer response to treatment (Treasure et al., 2014) [28]. Finally, it was interesting to note that reports of increased compassion and tolerance were greater in Treatment As Usual than in either of the intervention groups. It may be the case that carers become accepting and acquiescent whilst living alongside AN, whereas carer interventions focus on addressing symptoms within the spirit of emotional intelligence, by using communication techniques, challenging comfort zones, promoting responsibility and using consistent non-negotiable boundaries. Further research would be required to examine this point further.

Patients

Overall, there appears to be a higher frequency of patients reporting greater understanding, awareness and coping, improved relationships and a calmer emotional and behavioural climate in the intervention groups (E and EC) over Treatment As Usual. This is consistent with ethos taught by the ECHO skills training interventions (Goddard et al., 2011; Pepin & King, 2013; Goddard et al., 2010; Hibbs et al., 2015a;) [9, 12, 29, 30]. Results are also consistent with a previous phase of our work where we compared the ECHO intervention with Treatment As Usual in adult patients and their caregivers. It is useful to compare feedback from the two groups in terms of providing relevant information and skills for future intervention development. Again, patients' perceptions of greater understanding, awareness and coping abilities, improved relationships and communication and reduced criticism, overprotection and carer anxiety was more frequent in the intervention group (Macdonald et al., 2014) [15].

It is also interesting to note that when comparing the feedback

of adolescents in the earlier stage of AN with our previous work using the intervention with people at a severe, enduring phase of illness, higher endorsement of the intervention was found from both patients and caregivers in the adult group (Macdonald et al., 2014) [15]. Negative aspects of participation, for example, were reported with greater frequency in the intervention groups. It is also possible that the motivational style of coaching may not have matched the needs of caregivers in the early phase of illness. Bill Miller, for example, suggests that motivational interviewing is not appropriate when people are in action (Miller & Rollnick, 2009) [31]. For example, one caregiver did not find the reflective element helpful. It may be the case that a more directive CBT type of coaching might be more beneficial in this group. Meanwhile, some caregivers reported additional needs that were not covered, such as the possible need to consider the overlap with autistic spectrum traits. An individually tailored caregiver intervention would involve working initially on a needs assessment, discussion of change objectives before developing a practical plan, along with adoption and implementation.

Limitations

The main limitation was the use of a written feedback approach as opposed to a semi-structured interview which would have made it possible to clarify those responses of a more ambiguous nature, as well as eliciting richer and more meaningful data. Another limitation was that only half of the patients in the study provided feedback compared to the higher number of carers who provided data which may have led to a bias towards those who were particularly engaged in the intervention. There may also have been a time lapse between outpatient attendance and receipt of feedback response form. A number of patients, for example, experienced confusion over what particular time period to which the questions referred. Finally, this feedback highlighted problems in the design of the study. It appears that the information given to patients about the study was considered to be unhelpful or incorrect and some participants felt coerced. Also, the background level of dissemination of the basic aspects of the intervention is quite high with caregivers in all groups attending workshops and accessing the materials. Consequently, this appears to have resulted in some contamination in the Treatment As Usual group.

Strengths

The main strength of this study is that, as far as we are aware, it is the first study to have explored in detail, the experience of adolescent outpatients and their caregivers' participation in a skills training intervention. Another strength was the reasonably high return of caregiver feedback questionnaires. Furthermore, it is possible to compare experiential perspectives across stage of illness between younger and older patients as the same intervention was used and measured in earlier phases of the research (Macdonald et al., 2014) [15]. Finally, blinding of assessors is also strength in terms of study methodology.

Conclusion

Changes in caregiver behaviours and attitudes are noted both

by caregivers and patients, when caregivers have access to the skills training intervention. We did not find major differences in the relevance of these materials for people in the early versus severe and enduring stage of illness. The background level of caregiver support and information is greater in the adolescent group than in our study of adults but this may be because of a general increase in dissemination rather than being related to the age of the participants. However, some comments suggest that the timing and pace of the intervention may need to be different in the adolescent group.

This study illustrates how caregiver skills training materials are successfully used by caregivers to change their behaviours. These changes in style are observed by patients as well as by caregivers themselves. Moreover, this approach can be easily disseminated and may play an important role in breaking some of the barriers to early intervention in this patient group.

Competing Interests

JT is an author of the book used in the ECHO intervention (Treasure et al., 2007). RH, CR, EG, PM and GT provided coaching in the ECHO treatment arm.

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