

Expert Carers Helping Others (ECHO)

A case study on
carer involvement in
mental health research



Acknowledgements

This case study was written by Dr Sarah Robens, Anthropologist at Devon Partnership NHS Trust, on behalf of the Mental Health Research Network West Hub.

Study summary

ECHO is a guided self-help intervention that includes a published book and a DVD which demonstrates how to support and promote recovery in Anorexia Nervosa for carers. The intervention includes 10 telephone coaching sessions, and the majority of the coaches are also carers with lived-experience of having supported a loved one with an eating disorder.

The ECHO programme is being studied as part of a Randomised Control Trial (RCT), to look at the impacts of the use of ECHO on Anorexia Nervosa symptoms. The study is also looking at the impact on the carers and the "expert carer coaches", as well as other outcomes.

The RCT is being carried out on 35 NHS sites, and involves 149 families.

The chief investigator is Professor Janet Treasure at King's College London.



The ECHO team

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Carer involvement in this study

In this particular case, carer involvement is in the origins and development of the programme itself (the self-help intervention) as well as in the running of the intervention, through telephone coaching support.

In fact, the programme itself would not exist without carers. In the late 1990s, staff on the eating disorders ward of South London and Maudsley Eating Disorders Unit, were aware that carers did not feel involved in what was going on with the treatment of their loved one. In response to this, carer conferences and on-ward workshops were started up, to discuss issues and inform people about relevant research and innovations in treatment. It became clear that the family therapy being offered to carers was not seen as a positive experience, but what would benefit carers would be support to learn listening skills and motivational forms of communication.

As approaches to eating disorder treatment evolved on the ward, the issue of communication and interaction was seen as increasingly important. This corresponded to a general shift in opinion in the 2000s, which saw a shift to the importance of promoting emotional communication and literacy within family structures as part of the treatment of Anorexia Nervosa. Researchers recognised the impact of family interactions on Anorexia Nervosa, and this knowledge, coupled with the need of the carers for more involvement in treatment, led to the decision to work on a programme for carers.

A 3-day workshop about communication was held for carers of inpatients, and found to be very successful. In particular, the interpersonal aspect of the workshop was appreciated by carers and seen to have a very positive impact. Following on from this, further workshops were held in which carers were offered training to give them the skills and knowledge needed to be a coach. The workshops aimed to consider the problems of high expressed emotion, overprotection, misattributions about the illness and unhelpful methods of engaging with the eating disorder symptoms. In order to facilitate the spread of these skills, the next phase saw the development of DVDs accompanied by a manual and telephone coaching. This was the fore-runner to the ECHO project now being tested.

Now that ECHO is being tested, carers are involved as coaches in the delivery of the programme, but they are also included in discussions about the RCT.

Throughout the whole process, carers have been at the heart of what is happening. This is a system that started because of the concerns expressed by carers, and they have been listened to and included from the origin of the project, to the testing.

How carers are supported during their involvement

Carer coaches are trained to deliver motivational interviewing, and provide telephone coaching to other carers. In so doing, they are required to stick to a programme of support which should not involve using their own direct experience (for example, they cannot respond by saying –“I remember when my daughter was like that, we tried the following...”), but rather should support the development of the trainees’ approach to communication. This can be quite difficult for carer coaches, but the system involves checks of how the telephone coaching is happening, and supervisors feed back to carer coaches.

Importantly, it can also be difficult for carers to listen to others’ problems which can be so similar to their own deeply troubling times. However, the carer coaches receive a lot of supervision. They attend monthly sessions where they receive training top-ups. Coaches undertake one-to-one supervision on a regular basis and have access to a supervisor whenever needed. Supervisors have both clinical and caring experience and are quick to respond when needed.

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The benefits the carers felt they gained from being involved in the project

As with other more typical “involvement in research” projects, carers involved in coaching roles for ECHO have expressed how their involvement gives them knowledge and support from others. They have also related how there are positive transferable effects of the coaching, both in terms of helping them in their situations at home, but also sometimes elsewhere. Some have reported how the skills they learn from coaching are transferable to the workplace, for example.

Some coaches expressed how their involvement has improved their self-belief and confidence, giving them a sense of personal development. Along the same lines, there have also been reports of self-fulfilment, feeling that they are doing something worthwhile and feeling good about themselves for it.

The impact of involving carers on the project itself

Carer involvement in relation to eating disorders has traditionally been minimal and this project changes that. What has developed out of this trial is one of the only approaches to eating disorders that involves carers and families. Because carers are at the centre of this project, topics that are sometimes difficult to approach can be more easily approached. For example, eating disorders can lead to many feelings of blame, and in this programme, such issues are addressed in a way which has been discussed and agreed with carers themselves.

Carer coaches have spoken of the diverse experiences they bring to their role when coaching other carers of people with an eating disorder. In some cases that experience is not just the personal experience of being a carer, but also their broader life and work experience, for example as counsellors or teachers.

Carer coaches also report their great belief and passion for the programme and for what they are doing. They are fully committed, highly motivated and hard-working in what they do, because they know the difference it can make to other carers' lives and people diagnosed with Anorexia Nervosa.

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Challenges that the carers faced

As mentioned earlier, carer coaches are required to minimise the use of direct examples from their own experience, which some find difficult. There are also difficulties faced when a loved one is very ill, and at some times, coaches can easily back-out of commitments until such a time as they are ready to resume. Other problems reported have included time constraints, as coaching can take quite a lot of time.

Lessons to be learnt from this study

- This is an impressive example of researchers and clinicians learning from carers of the patients they see in their everyday work. The study shows the benefits of involving carers in the inception of a research idea, developing a treatment solution and delivering the intervention itself.
- The study highlights that to successfully involve carers in delivering an intervention, frequent supervision and support for carers is needed, as demonstrated in this project.
- The study demonstrates that such an approach to supporting carers produces beneficial outcomes to the people they care for with Anorexia Nervosa.
- It is important to recognise that carers are people too. The value that these carers added to the research study came not only from the fact that they were carers, but that they came from all walks of life and could draw upon their educational, professional and voluntary experiences when delivering coaching sessions.



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