


Family members' perspectives on the acceptability and impact of a co-facilitated information programme: the EOLAS mental health programme

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Background: Despite the critical role families play in the care and recovery journeys of people who experience enduring mental distress, they are often excluded by the mental health services in the care and decision-making process. International trends in mental health services emphasise promoting a partnership approach between service users, families and practitioners within an ethos of recovery.

Objective: This paper evaluated the acceptability of and initial outcomes from a clinician and peer co-led family information programme.

Methods: A sequential design was used involving a pre-post survey to assess changes in knowledge, confidence, advocacy, recovery and hope following programme participation and interviews with programme participants. Participants were recruited from mental health services running the information programme. In all, 86 participants completed both pre- and post-surveys, and 15 individuals consented to interviews.

Results: Survey findings indicated a statistically significant change in family members' knowledge about mental health issues, recovery attitudes, sense of hope and confidence. In addition, the interviews suggested that the programme had a number of other positive outcomes for family members, including increased communication with members of the mental health team and increased awareness of communication patterns within the family unit. Family members valued the opportunity to share their experiences in a 'safe' place, learn from each other and provide mutual support.

Conclusion: The evaluation highlights the importance of developing information programmes in collaboration with family members as well as the strength of a programme that is jointly facilitated by a family member and clinician.

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Introduction

Recovery-oriented services are the gold standard to which mental health services currently aspire. Although there are many different definitions of recovery, there is general consensus that recovery refers to an approach that promotes an individual's resourcefulness, autonomy, positive sense of self and belief in their ability to live a meaningful life (McCabe *et al.* 2018). A core principle underpinning the recovery approach is equal partnership between all stakeholders in the planning, delivery and evaluation of mental health services (Keogh *et al.* 2014). Although historically family members have felt

excluded by mental health service providers, in more recent times, national and international mental health policies emphasise the pivotal role of families in recovery-oriented services (e.g. Department of Health and Children, 2006; Mental Health Commission, 2007; World Health Organization, 2010; International Mental Health Collaborating Network Charter, 2013). Best practice guidance acknowledges the importance of building family members' capacity to impact positively on people who experience severe mental distress (NICE, 2009; Schiffman *et al.* 2015; Health Service Executive, 2017).

While recovery for service users entails a degree of autonomy and connection with self (Kartalova-O'Doherty *et al.* 2012), connectedness with others is an integral part of the recovery process (Slade, 2009; Gehart, 2012). Harnessing positive aspects from the

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social environment, such as positive interpersonal interactions and relationships, is central to many people's recovery (Topor *et al.* 2006; Wyder & Bland, 2014; Reupert *et al.* 2015). Conversely, exposure to negative aspects of social environments, such as involvement in negative relationships, may be experienced as disempowering. This can prompt withdrawal from relationships in order to protect personal well-being (Watts & Higgins, 2017). Relationships, however, are not universally positive or negative (Onken *et al.* 2007; Tew, 2013), but dynamic processes involving adjustment and negotiation as the recovery journey unfolds (Topor *et al.* 2006; Wyder & Bland, 2014). As people with mental health problems often live with or are supported by family members, these individuals have a significant role in the person's mental health recovery (Wyder & Bland, 2014). Family members may be the first to recognise distress and intervene to access support for the person. They may also share their knowledge of the individual with service providers, act as the person's advocate and provide a range of other financial, instrumental and emotional support (Topor *et al.* 2006; Reupert *et al.* 2015).

Although family members are recognised as valuable partners in recovery, they report little experience of recovery-oriented services and partnership (Hungerford & Richardson, 2013). They receive limited information from service providers (Kartalova-O'Doherty *et al.* 2008; Cleary *et al.* 2014; O'Féich *et al.* 2019) and lack knowledge of the philosophy of recovery, how to access services as well as the treatments and support available (van de Bovenkamp *et al.* 2010; Hungerford & Richardson, 2013). Family members also report experiencing a conflict between practitioners' desire to maintain the person's rights to confidentiality around diagnosis and treatment, and their own need to understand how best they can support and help the person in difficulty (Kartalova-O'Doherty *et al.* 2008). Consequently, they express a desire for knowledge on mental health issues, in addition to information about how to communicate and maintain positive social relationships with their relative (Solomon, 2004; Jormfeldt *et al.* 2010; Cleary *et al.* 2014; O'Féich *et al.* 2019). This paper reports the findings of a study that evaluated the acceptability and impact of a co-facilitated, mental health information programme designed for families of people with psychosis as part of the EOLAS mental health information project (EOLAS is the Irish word for knowledge).

EOLAS mental health information project

The EOLAS Programme for Families and Friends is part of a recovery project involving service users, family

members, clinicians and academics who co-produced, co-delivered, co-managed and evaluated two mental health information programmes (one for people who have been diagnosed with schizophrenia spectrum or bipolar disorders and a parallel programme for their family members or other supporters).

The family programme consists of 8 weekly sessions, each of 90 minutes' duration. While no theoretical perspective is privileged, and information on medical, psychological and social perspectives are presented, all the programme content are presented within a recovery ethos and underpinned by the principles of adult learning. The programme focuses on enabling family members to understand how mental health services work, the role of team members, bio/psycho/social treatment options, how to access services and support, how to improve communication within the family and how to care for their own mental health. Furthermore, issues of stigma, coping, advocacy and personal recovery are discussed. Two separate handbooks with information pertaining to each session have been developed (one for the facilitators delivering the programme and one for the participants).

One of the core differences between the EOLAS programmes and other family programmes is the dual nature of the facilitation as it incorporated both peer and clinician facilitation. This dual model of facilitation recognises the potential benefits derived from both peer and clinician involvement in the delivery of education. While the value of clinician input in education is recognised (Lefley, 2009), education programmes designed and led solely by professionals tend not to incorporate recovery-focused content (McNeil, 2013). Furthermore, peer involvement in education recognises the value of experiential knowledge and facilitates the support, empathy and hope provided by peers (Solomon *et al.* 1997; Resnick *et al.* 2004; Barber *et al.* 2008; Resnick & Rosenheck, 2008; Watts & Higgins, 2017). More detailed information on the participatory approach taken to co-designing the programmes, the programme content and the process used to prepare the facilitators to co-deliver the programme are reported elsewhere (Higgins *et al.* 2017a,b; Higgins *et al.* 2018).

The present study

Prior to scaling up an intervention, work is required to examine the acceptability of both the intervention and evaluation protocol. Consequently, the present study examined the acceptability and initial outcomes from the family EOLAS programme using a single-group pre-post design. Data on outcomes were collected in order to better understand the potential impact and inform the ongoing development of the programme. The outcome measures were aligned with the

programme's focus on recovery. Consequently, changes in knowledge, confidence, recovery attitudes, advocacy and hope over the course of the programme were assessed. The relationship between changes in the programme's outcomes was also examined. In addition, qualitative interviews were conducted with participants to develop a greater understanding of their experiences of the programme and the acceptability of the peer-clinician facilitation element.

Methods

A sequential design was used: quantitative data assessing programme outcomes were collected before qualitative data exploring participants' experiences were obtained. This approach was selected to meet the different objectives of the study; however, the quantitative results did not influence the direction of the subsequent qualitative aspect.

Participants

Following receipt of ethical approval by the Faculty of Health Sciences Research Ethics Committee at Trinity College, Dublin and ethics committees of the participating mental health services, potential family member participants were given an information sheet about the study when they were being recruited to attend the EOLAS information programme. At that time, they were informed that they could choose to participate in the programme without obligation to participate in the research. On day 1 of the programme, participants were given an envelope containing the questionnaire and an information sheet. They were requested to complete the questionnaire and return it in the envelope provided, and if they did not wish to be involved, they were informed that they could return an incomplete questionnaire, thereby facilitating anonymity for participants. The post-programme questionnaire was distributed at the end of the final EOLAS session. The post-programme pack included an opt-in form for the semi-structured interviews, which participants could complete immediately or return at a later time to researchers in the stamped addressed envelope provided. Subsequently, researchers contacted individuals who expressed such interest to discuss participation and schedule interviews with those consenting to participate. Individual interviews were held with participants 2–4 weeks post-programme.

Procedure

Quantitative data were collected using a pre-post design whereby questionnaires were completed prior to and immediately after programme participation. The pre-programme questionnaire collected demographic data

on participants. Given the unique nature of the programme, the questionnaire battery comprised a mixture of validated established measures for key outcomes (e.g. recovery attitudes and hope) and scales developed by the research team to be sensitive to the specific key learning outcomes of the programme. A 10-item knowledge scale was developed to assess participants' knowledge of a range of mental health issues. This was scored using a 5-point Likert scale ranging from 1 (poor) to 5 (excellent); Cronbach's α was .88. Participants' confidence in their own ability to cope and their confidence in accessing help for their family member with the mental health difficulty were assessed using a 9-item scale ranging from 1 (not at all confident) to 4 (very confident); Cronbach's α was .85. Advocacy was evaluated using an 11-item scale ranging from 1 (strongly disagree) to 5 (strongly agree). The scale was based on Brashers *et al.* (1999) Patient Self-Advocacy Scale and Cronbach's α was .72. To assess changes in attitudes towards recovery, the widely used and validated Recovery Attitudes Questionnaire 7 (RAQ-7) (Borkin *et al.* 2000) was used. The RAQ-7 had a Cronbach's α of .70. Hope was assessed using two items from the psychometrically supported Herth Hope Index (Herth, 1992); these items were selected on the basis of their match to the programme's content and they had a Cronbach's α of .68.

The post-programme questionnaire replicated the pre-programme questionnaire and was supplemented with closed questions to elicit information on the number of sessions attended, satisfaction with the programme and perceived usefulness of programme. Open-ended questions elicited participants' views on the most and least helpful aspects of the programme and yielded additional comments about the programme. The semi-structured interviews with participants were informed by a topic guide developed by the research team. During the interviews, participants were prompted to discuss their personal experience of the programme and the co-facilitation aspect of it, its impact on their lives as well as its impact on other family members.

Data analysis

Quantitative data were analysed using SPSS version 22. Categorical data are summarised using frequencies (*n*) and percentages (%); continuous data are summarised using means (*M*) and standard deviations (*s.d.*). The mean scores on scales were calculated, with higher scores on each of these scales representing more positive outcomes. A series of paired sample *t* tests were conducted to examine changes in knowledge, confidence, advocacy, recovery attitudes and hopes for the participants from Time 1 (T1) to Time 2 (T2).

Table 1. Clinical—demographic profile of participants

		% (n)
Gender	Male	28.9 (24)
	Female	71.1 (59)
Relationship status	Married/Partner	76 (57)
	Single	10.7 (8)
	Widowed/separated/ divorced	13.4 (10)
Education attainment	Completed Primary	10.8 (8)
	Lower/Upper Secondary	48.6 (36)
	Completed Third Level	40.5 (30)
Relationship to family member	Parent	65.1 (54)
	Sibling	15.7 (13)
	Spouse/Partner	18.1 (15)
	Sister-in-law	1.2 (1)
The diagnosis made in the family member	Schizophrenia	40 (30)
	Bipolar	25.3 (19)
	Schizoaffective	5.3 (4)
	Psychosis	14.7 (11)
How did you hear about EOLAS	Other ^a	14.7 (11)
	Mental health worker	84.2 (64)
	Family/friend with mental health problem	7.9 (6)
Number of EOLAS sessions attended	Other	7.9 (6)
	Eight	56.3 (45)
	Seven	27.5 (22)
	Six	11.3 (9)
	Five	3.8 (3)
	Four	1.3 (1)

^aOther: multiple disorders (6); depression anxiety (3); disassociation (1) and no diagnosis (1).

Due to the non-normal distribution of change scores Spearman ρ correlations examined the relationships between changes in variables. Given the number of comparisons conducted, and in order to balance Type 1 and Type 2 errors, statistical significance was set at an adjusted level of .01.

All interviews were audio recorded, transcribed verbatim and entered into the software package NVivo version 8. Thematic analysis, guided by the constant comparative process (Glaser & Strauss, 1967), was performed whereby data were systematically coded for ideas and concepts, emerging codes were compared for similarity and differences and merged into higher themes. To enhance the rigour of the qualitative analysis, data were analysed independently by two members of the team and findings compared.

Results

Participant profile

In total, 168 surveys were completed at T1 and 121 at T2. Paired analysis was carried out on 86 surveys.

Table 2. Impact of programme on outcome variables

	Pre M (s.d.)	Post M (s.d.)	Effect size (d)
Knowledge	2.55 (0.85)	3.47 (0.66)***	1.08
Confidence	2.15 (.59)	2.73 (.65)***	0.98
Recovery attitudes	3.99 (.40)	4.14 (.37)***	0.38
Hope	6.30 (2.26)	7.13 (2.04)***	0.37
Advocacy	3.40 (.48)	3.47 (.46)	0.15

*** $p < .001$.

Table 1 presents the profile of participants who completed surveys at both time points. The sample was predominantly female (71.1%, $n = 59$) with a mean age of 55.5 years ($s.d. = 12.02$, range 19–77). Nearly two thirds were parents of the family member (65.1%, $n = 54$), and the majority (86.6%, $n = 71$) reported that their family member had received a formal diagnosis of a mental health problem, with schizophrenia being the most common diagnosis. More than half the sample (56.3%, $n = 45$) attended all eight sessions and over a third (38.8%, $n = 31$) attended either seven or six sessions. None of the participants attended less than three sessions. There were no statistically significant differences between those who provided data at T1 only and those who completed both T1 and T2 questions in relation to demographic factors (gender, age, marital status, educational level), clinical factors (received a diagnosis, diagnostic category) or baseline psychological factors (knowledge, confidence, advocacy, recovery, hope).

A total of 15 programme participants (5 men and 10 women) participated in the interviews. Their age ranged from 46 to 70 years ($M = 59$ years). Participants were mostly mothers ($n = 8$), three were fathers, two were sisters, one was a mother's partner and one was a brother. Most had a family member with a diagnosis of a schizophrenia spectrum disorder ($n = 12$). The average duration of the family member's mental health difficulties was 13 years, ranging from 18 months to 43 years. Twelve reported that their family member lived with them, while three lived outside the family home. All except one family member were still in contact with mental health services. Most participants reported that they attended at least seven of the EOLAS sessions. Only 3 of the 15 family members had previously attended any kind of mental health information session.

Outcome evaluation

Prior to programme participation, overall knowledge among participants was below the midpoint of

Table 3. Relationships between changes in programme outcomes

	Confidence change	Recovery (RAQ) change	Advocacy change	Hope change
Knowledge change	.60***	.40***	.32**	.11
Confidence change		.23*	.33**	.32**
Recovery (RAQ) change		-	.05 ^{ns}	.07 ^{ns}
Advocacy			-	.17

RAQ, Recovery Attitudes Questionnaire.

* $p < .05$, ** $p < .01$, *** $p < .001$.

the scale. A statistically significant higher level of overall knowledge was found post-programme (Table 2). The programme significantly increased participants' overall confidence. Although participants showed positive attitudes towards the principles of recovery before participating in the programme, there was a statistically significant increase in such positive attitudes after the programme. The increase in feelings of hope was also statistically significant. However, there was no statistically significant improvement in advocacy overall from pre- to post-programme.

Relationship between changes in programme outcomes

To further examine the changes in the programme outcome variables, a correlation analysis was conducted on the change scores (See Table 3). A number of statistically significant relationships were found: increases in knowledge were associated with increases in confidence, recovery attitudes and advocacy; and increases in confidence were associated with increases in recovery attitudes, advocacy and hope.

Satisfaction and usefulness

To explore perceived satisfaction and usefulness, analysis was completed on all the completed post-programme surveys ($n = 121$). Almost all (96.7%, $n = 117$) of the participants who completed the post-programme surveys were either satisfied or very satisfied with the programme. An overwhelming majority also reported the programme to be either very useful ($n = 95$, 78.5%) or useful ($n = 23$, 19%). There was a strong correlation between satisfaction and perceived usefulness of the EOLAS programme (Spearman $\rho = .65$, $p < .01$), such that those who were more satisfied rated the programme as being more useful. Satisfaction

was not significantly associated with participant age ($\rho = .033$, $p = \text{NS}$) or number of sessions attended ($\rho = .065$, $p = \text{NS}$). There were no significant differences in satisfaction levels between males ($M = 4.69$) and females ($M = 4.70$) [$t(51) = 0.07$, $p = \text{NS}$]. Similarly there were no differences in satisfaction levels related to educational level [$F(3,70) = 0.48$, $p = \text{NS}$].

Interviews

Analysis of the interviews resulted in the following five themes: Enhanced knowledge of mental health issues, enhanced confidence to engage with service providers, increased awareness of communication within the family unit, importance of self-care and value of peer support.

Enhanced knowledge of mental health issues

Participants recounted difficulties trying to access information at critical junctures in their family member's mental illness trajectory, such as at the time of admission or diagnosis. The information acquired through the programme was cited as extremely useful, particularly in comparison to the information available from other sources, such as the literature, the Internet or mental healthcare interactions:

... I felt that from an information point of view it [course] was fantastic ... every week you got something new. Whether it was the explanation of the family supports or State Aid available, each week I came home thinking 'God you know I am after learning something and it was 2 hours really well spent'. (Participant 6)

Consistent with the quantitative findings, participants identified increased knowledge on mental health issues, including diagnosis, terminology, medication, psychosis, the Mental Health Act and resources for support. In addition to learning about different medications, the side effects and importance of following prescription guidelines, the module on medication gave participants an opportunity to have meaningful interactions with a psychiatrist and obtain responses to questions they had for a long period of time:

... and a doctor would come give an understanding to the medication and the way that it works. I just can't put word on how beneficial it was for me. (Participant 5)

In relation to the Mental Health Act (2001), despite some participants' lived experience of having a family member detained under the Act, participants reported a lack of understanding of the legislation and the programme appeared to redress this deficit effectively:

... really useful things, one was the voluntary versus involuntary admissions ... this was an issue for us [family] in the past ... there is an assistance admission team that I hadn't heard of (Participant 10)

Enhanced confidence to engage with service providers

Although there was no statistically significant improvement in advocacy in terms of quantitative scores, some participants reported feeling more confident (as a result of enhanced knowledge) to engage with and question practitioners about care and treatment. It also helped family members advocate for greater involvement in the decision-making process:

Certainly [EOLAS] gave me an understanding on the questions to ask, even on medication. Initially, I had a great confidence in a doctor. If they gave him [family member] a medication, he needs it, so take it ... when I lived with (family member) and seen what the dosage was doing to him ... I said to his doctor 'We just had to find a different way'. The fact that I learned so much on the course. I was able to ask the questions and for the two of us to make a decision, a very risky decision to say he's on no medication. I'm living every day and I'm marking it on the calendar, another day without medication Everything is going good (Participant 9)

Increased awareness of communication within the family unit

Through the programme, participants reported becoming more aware of how to recognise early warning signs of their family member's distress as well as becoming aware of negative patterns of communication that escalated to confrontation. They also reported enhanced skills to respond to their family member's distress in a more empathetic manner and to formulate a plan to manage challenging situations, which previously were experienced as overwhelming:

EOLAS was a God-send because I was in the dark, I was like a zombie walking the streets No direction, no plan, no understanding ... I would have judged or chastised ... done everything wrong Now I'm not a headless chicken. Now I know how to talk to him and it was through the course that I developed these skills (Participant 11)

I just couldn't deal with it and with the knowledge (gained from the EOLAS programme) I just said 'count to ten and keep calm (says own name)

stop shouting or screaming, deal with it in a quiet manner ... since the EOLAS programme I seem to be dealing with everything in a much calmer fashion. (Participant 5)

In tandem with a greater awareness of how to respond to their family member's distress, the programme had a positive impact on communication within the family unit, with participants leading the way in opening discussions with other family members. For some this was a departure from old habits of 'bottling up' emotions and avoiding communication in order to 'stay strong':

I would go through it [content] with his Dad what went on at the class. ... We're [family] talking through things more and overall I say we're communicating a lot better, more open about our own feelings on the matter. I would have bottled up a lot of my tension and they [children] are letting us know how they're feeling a bit more. (Participant 15)

Importance of self-care

The programme emphasised not only the importance of safeguarding their own personal mental health but also the importance of self-care as a prerequisite to being able to provide support to another person.

They laid heavy emphasis on the fact that you have to ... to be any use to the patient, you have to be firing on all cylinders yourself, mentally and physically and in order to do that you just need that little bit of a break (Participant 3)

Value of peer support

In addition to the value of the information gained, the peer aspect of the programme emerged as an integral part of its success. The experience of learning through mutual sharing not only provided valuable experiential knowledge, but it reduced the sense of isolation participants described hitherto experiencing, providing them with much needed emotional support.

I have done a lot of reading myself. I had done a lot of researching and googling ... and I supposed I felt quiet isolated ... I had never experienced that level of support or anyone else who had experienced the same as me (Participant 11)

The peer facilitators' openness and willingness to share their lived experience enabled participants to realise that their feelings and experiences were not unique but were shared, thereby validating their experiences:

She (peer facilitator) was quite open about sharing her experience; a very wise person I suppose you realise you haven't done anything wrong, that everybody has reached the same stages, same peak, the same despair that you've reached ... (Participant 10)

It was great that (peer facilitator) had self-experience of when things go wrong and he had been there at the cold face when stuff goes wrong ... you were dealing with somebody who had been through it just like you (Participant 6)

The mutual sharing reinforced participants' realisation that they were not 'alone' and for many it was a valuable opportunity to speak about their own distress and needs, which was experienced as cathartic:

That's where the peer support actually really helped as well again it wasn't really a feature of the EOLAS programme ... but actually hearing people, and also people had a need to speak and I found myself that I had a real need to talk. (Participant 10)

Everyone is in the same boat as yourself and you were able to speak out and not feel stigma attached to your situation where everyone would have the same and maybe worse. (Participant 5)

The programme also provided sustained opportunities for reciprocal emotional support, with participants reporting that friendships were formed and contact between participants continued after the programme ended.

Discussion

The current study provides evidence that the EOLAS co-facilitated information and learning programme is acceptable to family members and is associated with positive recovery outcomes in terms of enhanced knowledge, confidence and hope, with further insights provided through interviews in relation to the processes and conditions within the programme that may account for the positive outcomes. To date, there are only a handful of evaluations of educational interventions modelled on co-facilitation (Solomon *et al.* 1997; Pratt *et al.* 2011; Coulthard *et al.* 2013; Green *et al.* 2013), and even fewer programmes focused on families with which the authors can directly compare this study's findings. Solomon *et al.* (1997) showed that group family workshops co-facilitated by a mental health specialist and a trained family member positively impacted on family members' self-efficacy to

manage and cope with their relative's mental distress. Their findings mirror the increased self-efficacy alluded to by participants in this study in terms of feeling more confident, empowered and better able to respond to their relative's distress as well as advocating for greater involvement in the decision-making process around the person's care.

The emotional climate within families can influence recovery, with expressed emotion an established factor in short-term relapse in schizophrenia (Kavanagh, 1992; Bebbington & Kuipers, 1994; Butzlaff & Hooley, 1998). A lack of knowledge about mental health problems can result in family members interacting with their relative in ways that are unhelpful; the inverse is also true, with more knowledge and education family members' ability to contribute positively to recovery is enhanced (Aldersey & Whitley, 2015). The EOLAS programme redressed information deficits among family members and, similar to other studies, improved knowledge of mental distress, the mental health system, self-care (Dixon *et al.* 2004; Pickett-Schenk *et al.* 2006; Pickett-Schenk *et al.* 2008; Chiu *et al.* 2013; Lucksted *et al.* 2013) and the Mental Health Act (2001). While the provision of knowledge is important, changing behaviour is the ultimate outcome. Although the evaluation was conducted within a short time of programme completion, similar to Bademli & Duman (2016) and Lucksted *et al.* (2008), this study indicated that the enhanced knowledge, confidence and insights gained resulted in participants becoming more conscious of their style of interaction with their distressed relative. This in turn facilitated changes in their communication strategies to deal with challenging and stressful situations and changes in the way they interacted with the wider family unit, with a greater willingness to engage in more open conversation within the family.

A key theme running through much of the writing on recovery is the centrality of hope, which has been described as a 'vital ingredient' and 'cornerstone' of recovery (Repper, 2012; Watts & Higgins, 2017). The EOLAS programme impacted positively on participant optimism about the future for both themselves and their relative, and on their attitudes towards recovery; such positive impact of the programme is important for a number of reasons. First, family members can diminish hope or co-create and maintain hope with the person (Wyder & Bland, 2014), with studies indicating that families who have a positive attitude towards recovery are more likely to hold and create hope for their distressed relative (Topor *et al.* 2006; Marshall *et al.* 2013). Second, higher levels of hope in family members is associated with less distress, caregiver burden and maladaptive coping (Geffken *et al.* 2006; Hernandez *et al.* 2013), including in family members who have a relative with a diagnosis of schizophrenia

(Friedman-Yakoobian *et al.* 2009). Third, given the ‘chronicity discourse’ that frequently surrounds discussion on diagnoses such as schizophrenia, improving family members’ perceptions of recovery can be achieved (e.g. in terms of it being possible for people to have a fulfilling and meaningful life even in the presence of enduring symptoms of mental distress).

Similar to other studies reporting the benefits derived from peer support in terms of emotional well-being (Pickett-Schenk *et al.* 2006; Pickett-Schenk *et al.* 2008; Jönsson *et al.* 2011; McNeil, 2013), EOLAS participants found the peer element of the facilitation acceptable and valued the opportunity to meet people in similar circumstances to themselves, share their experiences in a ‘safe’ place, learn from each other and provide mutual support. In addition, the space created appeared to help reduce participants’ sense of isolation, with some forming valuable emotional support networks, which were an ongoing source of support after programme completion.

Limitations

The absence of a comparison or control group limits any inferences about the programme’s impact. The self-selection recruitment process may have resulted in study bias with those who were more actively engaged in their relative’s care and more interested and positive about a recovery-based programme opting to participate. Furthermore, the sample comprised mostly female family members. As a result, it cannot be assumed that the views and experiences presented represent all of those who participated in the EOLAS programme. This may also account for the high advocacy scores among participants at baseline and the lack of a statistically significant increase from pre- to post-programme. In addition, the study measures the short-term impact of the programme; therefore, it is not possible to say whether the changes evident in areas such as knowledge and confidence were sustained in the medium term or long-term. Furthermore, measuring advocacy immediately after programme completion may have been too soon to allow for advocacy opportunities to arise and to be acted on by family members.

Conclusion

This study provides evidence that a co-facilitation approach to education is acceptable to participants and provides a means of increasing knowledge among family members as well as nurturing confidence and hope for the future. Furthermore, it demonstrates the value of both clinician and peer input into education and the processes by which family members’ self-efficacy in relation to supporting their relative’s

recovery can be facilitated. Rolling out and integrating the programme into services nationally may help address some of the deficits in family support identified in mental health reforms’ recent report on family/carers experiences of the Irish mental health services (O’Féich *et al.* 2019).

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Conflict of interest

The authors have no conflict of interest to report.

Ethical standards

The authors assert that all procedures contributing to the work comply with the ethical standards of the relevant institutional committee on human experimentation with the Helsinki Declaration of 1975, as revised in 2008. The study protocol was approved by the institutional review board of each participating institution. Written informed consent was obtained for all interviews.

References

- Aldersey HM, Whitley R (2015). Family influence in recovery from severe mental illness. *Community Mental Health Journal* 51, 467.
- Bademli K, Duman ZÇ (2016). Emotions, ideas and experiences of caregivers of patients with schizophrenia about “Family to Family Support Program”. *Archives of Psychiatric Nursing* 30, 329–333.
- Barber J, Rosenheck R, Armstrong M, Resnick S (2008). Monitoring the dissemination of peer support in the VA system. *Community Mental Health Journal* 44, 433–441.
- Bebbington P, Kuipers L (1994). The predictive utility of EE in schizophrenia: an aggregate analysis. *Psychological Medicine Psychological Medicine* 24, 707–718.
- Borkin J, Steffan J, Krzton E, Wishnick H, Wilder K, Yangarber N (2000). Recovery Attitudes Questionnaire: Development and evaluation. *Psychiatric Rehabilitation Journal* 24, 95–102.
- Brashers D, Haas S, Neidig J (1999). The patient self-advocacy scale: measuring patient involvement in health care decision-making interactions. *Health Communication* 11, 97–121.
- Butzlaff RL, Hooley JM (1998). Expressed emotion and psychiatric relapse: a meta-analysis. *Archives of General Psychiatry*, 55, 547–552.
- Chiu MYL, Wei GFW, Lee S, Choovanichvong S, Wong, FHT (2013). Empowering caregivers: Impact analysis of Family Link Education Programme (FLEP) in Hong Kong,

- Taipei and Bangkok. *The International Journal of Social Psychiatry* 59, 28–39.
- Cleary A, Walsh F, Dowling M** (2014). Family carers: lived experience of caring for relatives with an SMI. *British Journal of Mental Health Nursing* 3, 151–156.
- Coulthard K, Patel D, Brizzolara C, Morriss R, Watson S** (2013). A feasibility study of expert patient and community mental health team led bipolar psychoeducation groups: implementing an evidence based practice. *BMC Psychiatry* 13, 301–313.
- Department of Health and Children** (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. The Stationery Office: Dublin.
- Dixon L, Lucksted A, Stewart B, Burland J, Brown CH, Postrado L, McGuire C, Hoffman M** (2004). Outcomes of the peer-taught 12-week family-to-family education program for severe mental illness. *Acta Psychiatrica Scandinavica* 109, 207–215.
- Friedman-Yakoobian MS, de Mamani AW, Mueser KT** (2009). Predictors of distress and hope in relatives of individuals with schizophrenia. *The Israel Journal of Psychiatry and Related Sciences* 46, 130–140.
- Geffken GR, Storch EA, Duke DC, Monaco L, Lewin AB, Goodman WK** (2006). Hope and coping in family members of patients with obsessive-compulsive disorder. *Journal of Anxiety Disorders* 20, 614–629.
- Gehart DR** (2012). The mental health recovery movement and family therapy, part I: consumer-led reform of services to persons diagnosed with severe mental illness. *Journal of Marital and Family Therapy* 38, 429–442.
- Glaser BG, Strauss AL** (1967). *The Discovery of Grounded Theory: Strategies or Qualitative Research*. Transaction Publishers: Chicago.
- Green CA, Janoff SL, Yarborough BJ, Paulson RI** (2013). The recovery group project: development of an intervention led jointly by peer and professional counselors. *Psychiatric services* 64, 1211–1217.
- Health Service Executive** (2017). *Best Practice Guidance for Mental Health Services: Supporting you to meet Regulatory Requirements and towards Continuous Quality Improvement*. Health Service Executive: Dublin. <https://www.hse.ie/eng/services/list/4/mental-health-services/mental-health-guidance/best-practice-guidance/documents/best-practice-guidance-for-mental-health-services.pdf>
- Hernandez M, Barrio C, Yamada AM** (2013). Hope and burden among Latino families of adults with schizophrenia. *Family Process* 52, 697–708.
- Herth K** (1992). Abbreviated instrument to measure hope: development and psychometric evaluation. *Journal of Advanced Nursing* 17, 1251–1259.
- Higgins A, Hevey D, Boyd F, Cusack N, Downes C, Monahan M, McBennett P, Gibbons P** (2018). Outcomes of a co-facilitation skills training programme for mental health service users, family members and clinicians: the EOLAS project. *International Journal of Mental Health Nursing*, 27, 911–921.
- Higgins A, Hevey D, Gibbons P, O' Connor C, Boyd F, McBennett P, Monahan M** (2017a). A participatory approach to the development of a co-produced and co-delivered information programme for users of services and family members: the EOLAS programme (paper 1). *Irish Journal of Psychological Medicine* 34, 19–27.
- Higgins A, Hevey D, Gibbons P, O' Connor C, Boyd F, McBennett P, Monahan M** (2017b). Impact of co-facilitated information programmes on outcomes for service users and family members: the EOLAS programmes (paper 2). *Irish Journal of Psychological Medicine* 34, 29–37.
- Hungerford C, Richardson F** (2013). Operationalising recovery-oriented services: the challenges for carers. *Advances in Mental Health* 12, 11–21.
- International Mental Health Collaborating Network Charter** (2013). Charter (<http://imhcn.org/charter/>). Accessed 4 February 2019.
- Jönsson PD, Skärsäter I, Wijk H, Danielson E** (2011). Experience of living with a family member with bipolar disorder. *International Journal of Mental Health Nursing* 20, 29–37.
- Jormfeldt H, Rask M, Brunt D, Bengtsson A, Svedberg P** (2010). Experiences of a person-centred health education group intervention—A qualitative study among people with a persistent mental illness. *Issues in Mental Health Nursing* 33, 209–216.
- Kartalova-O'Doherty Y, Doherty D, Walsh D** (2008). *Family Support Study: A Study of the Experiences, Needs and Support Requirements of Families with Enduring Mental Illness in Ireland*. Health Research Board: Dublin.
- Kartalova-O'Doherty Y, Stevenson C, Higgins A** (2012). Reconnecting with life: a grounded theory study of mental health recovery in Ireland. *Journal of Mental Health* 21, 136–144.
- Kavanagh DJ** (1992). Recent developments in expressed emotion and schizophrenia. *British Journal of Psychiatry* 160, 601–620.
- Keogh B, Higgins A, DeVries J, Morrissey J, Callaghan P, Ryan D, Gijbels H, Nash M** (2014). 'We have got the tools': qualitative evaluation of a mental health Wellness Recovery Action Planning (WRAP) education programme in Ireland. *Journal of Psychiatric and Mental Health Nursing* 21, 189–196.
- Lefley HP** (2009). A psychoeducational support group for serious mental illness. *The Journal for Specialists in Group Work* 34, 369–381.
- Lucksted A, Medoff D, Burland J, Stewart B, Fang LJ, Brown C, Jones A, Lehman A, Dixon LB** (2013). Sustained outcomes of a peer-taught family education program on mental illness. *Acta Psychiatrica Scandinavica* 127, 279–286.
- Lucksted A, Stewart B, Forbes CB** (2008). Benefits and changes for family to family graduates. *American Journal of Community Psychology* 42, 154–166.
- Marshall S, Deane F, Crowe T, White A, Kavanagh D** (2013). Carers' hope, wellbeing and attitudes regarding recovery. *Community Mental Health Journal* 49, 344–353.

- McCabe R, Whittington R, Cramond L, Perkins E** (2018). Contested understandings of recovery in mental health. *Journal of Mental Health* **27**, 475–481.
- McNeil S** (2013). Understanding family-centered care in the mental health system: perspectives from family members caring for relatives with mental health issues. *Social Work in Mental Health* **11**, 55–74.
- Mental Health Commission** (2007). *Quality Framework: Mental Health Services in Ireland*. Mental Health Commission: Dublin.
- National Institute for Health and Care Excellence** (2009). *Schizophrenia: Core Interventions in the Treatment and Management of Schizophrenia in Adults in Primary and Secondary Care*. National Institute for Health and Clinical Excellence: London.
- O'Féich P, Mitchell K, Pérez S, McDaid S** (2019). *My Voice Matters: Report on a National Consultation with Family, Friends and Carers/Supporters of Mental Health Service Users*. Mental Health Reform: Dublin.
- Office of the Attorney General (2001). Mental Health Act 2001. (No. 25). Available at: <http://www.irishstatutebook.ie/eli/2001/act/25/enacted/en/print.html>.
- Onken SJ, Craig CM, Ridgway P, Ralph RO, Cook JA** (2007). An analysis of the definitions and elements of recovery: a review of the literature. *Psychiatric Rehabilitation Journal* **31**, 9–22.
- Pickett-Schenk S, Bennett C, Steigman P, Cook J, Lippincott R, Villagrancia I, Grey D** (2006). Changes in caregiving satisfaction and information needs among relatives of adults with mental illness: results of a randomised evaluation of family-led education intervention. *American Journal of Orthopsychiatry* **76**, 545–553.
- Pickett-Schenk S, Lippincott RC, Bennett C, Steigman P** (2008). Improving knowledge about mental illness through family-led education: the journey of hope. *Psychiatric Services* **59**, 49–56.
- Pratt CW, Lu W, Swarbrick M, Murphy A** (2011). Selective provision of illness management and recovery modules. *American Journal of Psychiatric Rehabilitation* **14**, 245–258.
- Repper J** (2012). *Recovery and Social Inclusion in Mental Health: Learning from Lived Experience*. John Wiley and Sons Ltd: Hoboken, United States.
- Resnick S, Armstrong M, Sperrazza M, Harkness L, Rosenheck R** (2004). A model of consumer-provider partnership: Vet-to-Vet. *Psychiatric Rehabilitation Journal* **28**, 185–187.
- Resnick S, Rosenheck R** (2008). Integrating peer-provided services: a quasi-experimental study of recovery orientation, confidence and empowerment. *Psychiatric Services* **59**, 1307–1314.
- Reupert A, Maybery D, Cox M, Scott Stokes E** (2015). Place of family in recovery models for those with a mental illness. *International Journal of Mental Health Nursing* **24**, 495–506.
- Schiffman J, Reeves GM, Kline E, Medoff DR, Lucksted A, Hoagwood K, Fang LJ, Dixon LB** (2015). Outcomes of a family peer education program for families of youth and adults with mental illness. *International Journal of Mental Health* **44**, 303–315.
- Slade M** (2009). *Personal Recovery and Mental Illness: A Guide for Mental Health Professionals*. Cambridge University: Cambridge.
- Solomon P** (2004). Peer support/peer provided services underlying processes, benefits, and critical ingredients. *Psychiatric Rehabilitation Journal* **27**, 392–401.
- Solomon P, Draine J, Mannion E, Meisel M** (1997). Effectiveness of two models of brief family education: Retention of gains by family members of adults with serious mental illness. *American Journal of Orthopsychiatry* **67**, 177–186.
- Tew J** (2013). Recovery capital: what enables a sustainable recovery from mental health difficulties? *European Journal of Social Work* **16**, 360–374.
- Topor A, Borg M, Mezzina R, Sells D, Marin I, Davidson L** (2006). Others: the role of family, friends, and professionals in the recovery process. *American Journal of Psychiatric Rehabilitation* **9**, 17–37.
- van de Bovenkamp HM, Trappenburg MJ, Grit KJ** (2010). Patient participation in collective healthcare decision making: the Dutch model. *Health Expectations* **13**, 73–85.
- Watts M, Higgins A** (2017). *Narratives of Recovery from Mental Illness: Role of Peer Support*. Routledge Taylor and Francis Group: Oxon and New York.
- World Health Organization** (2010). *User Empowerment in Mental Health: A Statement by the WHO Regional Office for Europe*. World Health Organization: Copenhagen.
- Wyder M, Bland R** (2014). The recovery framework as a way of understanding families' responses to mental illness: balancing different needs and recovery journeys. *Australian Social Work* **67**, 179–196.