



Volunteering as a community mental health educator: Positives and negatives for recovery

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Abstract

An advocacy role that is highly visible within the community is that of a consumer educator, when people with lived experience of mental illness use their personal experience to educate others in the community. This study investigated the positives and negatives for recovery of volunteering in an advocacy role as a consumer educator. A phenomenological qualitative research design was chosen, and semi-structured interviews were undertaken with 10 female consumer educators, aged between 20 and 59 years and with a wide range of diagnoses. Transcripts were analysed using a thematic analysis approach to identify themes within the data using a reiterative comparative procedure. The benefits of being a consumer educator far outweighed the negatives and four main themes emerged for the benefits: the unique value of peer support; the personal meaning gained from educating others about mental illness; the benefits of validation and catharsis through telling their story; and the skills gained. Negatives included feeling vulnerable during or after presentations, being fearful of stigma, and dealing with occasional challenges with co-presenters. This is one of the first studies of the effects on consumer educators of telling and re-telling their stories and 'coming out' in a public forum. It reveals substantial benefits for consumers in this advocacy role, but also shows that the role is not appropriate for all consumers and ongoing support in terms of screening, training, debriefing and peer support is vital.

Keywords

consumers, recovery, stigma, advocacy, qualitative

Introduction

Mental health consumer advocacy roles have expanded considerably over the past decade and now include roles such as consumer consultants, consumer support workers and consumer liaison workers (Australian Mental Health Consumer Network, cited in Rickwood, 2006). One advocacy role that is highly visible within the community is that of a consumer educator, which is when people with lived experience of mental illness use their personal experience to educate others in the community about mental

illness. This study investigated the positives and negatives for recovery of volunteering as a consumer educator.

A community-based non-government organisation in Australia that supports consumers to educate the community about mental illness is Mental Illness Education. This organisation operates in several Australian States and Territories, and in the Australian Capital Territory is known as Mental Illness Education-ACT (MIE-ACT). The objectives of MIE-ACT are to raise awareness and understanding of

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mental illness; improve mental health literacy; address myths and misconceptions regarding mental illness; reduce stigma; encourage early help-seeking behaviour; and impart information about local mental health resources (see www.mieact.org.au). The MIE-ACT program is delivered by people who have personal experience of mental illness, either as a consumer or carer. Volunteers are screened and trained to provide a standardised presentation augmented by their personal stories. In pairs, the presenters take high school class groups and other community groups through a single-session structured program that takes between 50 and 90 minutes. Presenters discuss myths about mental illness, explain stigma and provide factual information about the prevalence, symptoms and causes of mental illness. The presentations incorporate interactive activities to engage the audience and provide written material about mental health services and resources available in the community. Most importantly, however, the program was developed to emphasise the personal stories of the presenters.

In 2004, the interactive school-based MIE-ACT program was externally evaluated and shown to be effective at reducing the stigma of mental illness among young people and in increasing their mental health knowledge (Rickwood, Cavanagh, Curtis & Sakrouge, 2004). A fundamental element of the MIE-ACT program is the personal stories of the presenters, which are used to engage the students actively and to convey messages that de-stigmatise mental illness by showing that people with mental illness do recover and are ordinary people with a health condition that needs to be treated effectively. The research revealed that many students were deeply touched by the personal stories of the presenters and that this was a powerful medium. The personal stories made the impact of mental illness tangible and helped the realisation that people with mental illness were ordinary people who have survived extraordinary experiences. Both students and teachers reported that the personal stories were the most powerful factor in information delivery and attitude change (Rickwood et al., 2004).

It is the personal disclosure—through the personal stories of the MIE-ACT consumer educators—that makes an impact on the

audience and enables this type of advocacy to be effective. The main focus of advocacy roles in the mental health arena is to reduce the stigma surrounding mental illness by changing stigmatising attitudes and stereotypes (Rusch, Angermeyer & Corrigan, 2005). While the effectiveness of this form of advocacy by the MIE-ACT consumer educators has been demonstrated for participants (Rickwood et al., 2004), what has not been studied is the impact on the consumer educators themselves, and how this type of advocacy affects their mental health recovery.

Recovery is a unique and personal process, and each person with a psychiatric illness develops his or her own definition of personal recovery (Anthony, 1991). Nevertheless, common themes have emerged in the literature; when reviewing consumer definitions of recovery from the National Summit of Mental Health Consumers and Survivors (1999) *Recovery Plank*, Schiff (2004) found three major themes:

- recovery involves one's internal self—this involves believing in oneself, being able to help oneself and others, acceptance of self, loving oneself, and gaining self-confidence;
- recovery involves a social role—being able to use one's gifts and talents, to be needed, and to be productive; and
- recovery involves the way in which one interacts with one's environment and lives one's life—enjoying life, taking responsibility, not giving up, having freedom, feeling safe, living with hope, and making connections with others and with the world.

Peer support has been identified in numerous studies as an important factor in recovery (Solomon, 2004). Mead, Hilton and Curtis (2001) maintain that persons labelled with psychiatric disability become victims of social and cultural ostracism and consequently develop a sense of self that reinforces the 'patient' identity. However, when people identify with others who they feel are 'like them', they develop a connection. This connection or affiliation is a deep, holistic understanding based on a mutual experience where people are able to 'be' with one another without the constraints of traditional expert/patient relationships. Peer

support can offer a culture of health and ability as opposed to a culture of illness and disability (Curtis, 1999). Offering support, companionship, empathy, sharing and assistance counteracts feelings of isolation, rejection and discrimination (Gartner & Riessman, 1982).

Another theme in the recovery literature is disclosure. Disclosing one's mental illness can have both benefits and costs to the individual (Corrigan, 2000; Corrigan & Matthews, 2003). Benefits include a feeling of acceptance, increased self-esteem and decreased stress over keeping one's illness a secret, whereas the costs can include negative reactions such as social disapproval or rejection that stems from stigma (Corrigan & Matthews). Discussing mental illness experience has also been described as having a cathartic function: a release from the pressure of hiding the 'secret bottled up inside' (Herman, 1994). Rusch et al. (2005) state that the consumer is more likely to choose to disclose if they are in active consumer groups, regard mental illness as part of their life, and the recipient concerned has not shown discriminating behaviour. Advocacy and support groups made up of people 'coming out' can facilitate this process. Groups like these provide a range of services including support for those that are just 'coming out', recreation and shared experiences that foster a sense of community within a larger hostile culture, and advocacy/political efforts to further promote pride in the group (Kates & Belk, 2001).

In the case of MIE-ACT, the public education approach to advocacy that is undertaken means that the consumer educators are engaged in 'broadcasting', which is defined as seeking to educate people about mental illness by disclosing or speaking out publicly about personal experience of mental illness (Corrigan & Matthews, 2003). Broadcasting has additional benefits to disclosure in that it creates a sense of power over the experience of mental illness and the stigma associated with it, and thereby serves to enhance self-esteem.

Personal meaning is another strong theme in the first person recovery literature. As a result of mental illness, a person's original life goals may no longer be available and they may face the task of reassessing their values and goals in life and finding other ways of expressing their core

values (Mead et al., 2001). Many mental health consumers also experience the treatment in mental health services as a traumatising life event (Deegan, 1994). Following this, some people emerge with a sense of altruism and a survivor mission in order to create meaning in their illness (Roe & Chopra, 2003).

Strongly associated with the development of personal meaning is the role of storytelling. Storytelling involves a process of personal growth and development of a positive identity/self-concept through a process of telling and re-telling the story of one's illness (Mead et al., 2001). The theory behind the value of storytelling derives from narrative psychotherapy. Personal narratives are the stories people tell themselves and others to place experiences in context and make meaning of them. Storytelling is argued to assist mental health recovery in two ways: by reducing self-stigma and by assisting in positive identity development (Lapsley, Nikora & Black, 2002). Through reflection and insight, individuals come to see themselves in a more positive light and the mental illness as only part of who they are, not what defines them.

The current study aimed to explore the impact of being a consumer educator on mental health recovery. It investigated whether volunteer consumer educators identified benefits and/or costs related to their advocacy/educator roles that have impacted on their recovery from the experience of mental illness and treatment.

Method

A phenomenological qualitative research design was chosen as it was most congruent with the aims of this research. Phenomenological research procedures involve collecting in-depth descriptions from people who have experienced a particular phenomenon (in this case, being a consumer educator) and abstracting and summarising the key meanings in these descriptions as the basis for interpretation of the essential features of the phenomenon (Marks & Yardley, 2004). This approach examines the experience of the individual, and thus provides a 'space' or a 'voice' for the lived experience of different people, which are not adequately represented or analysed by methods that aggregate statistics from large samples.

Participants

Participants were 10 female current MIE-ACT consumer educators, aged between 20 and 59 years ($M = 40.9$, $SD = 11.4$). They had a range of diagnoses including depression, anxiety, bipolar affective disorder, schizophrenia, post traumatic stress disorder, borderline personality disorder, bulimia nervosa and anorexia nervosa. Length of time since diagnosis ranged from seven to 20 years ($M = 11.4$, $SD = 4.9$) and length of time as a consumer educator ranged from one to 11 years ($M = 5.2$, $SD = 3.0$). Eight out of the 10 participants had either completed or were currently completing tertiary education.

Procedure

Ethics approval was obtained from the University of Canberra Committee for Ethics in Human Research. As part of a larger study evaluating the value of MIE-ACT to consumer mental health recovery, all current and past presenters and some recently recruited future presenters were invited to participate in the research. To maintain privacy, the initial approach to potential participants was undertaken by the MIE-ACT executive officer; researchers did not have access to participants' personal information. Participants then indicated whether they were interested and organised with the researchers a suitable time for interview: 33 people were initially invited to participate and 30 agreed to participate in the study. There was a very high level of interest in participation.

Of the 30 potential participants, five were excluded because they were carer presenters rather than consumer educators, and another five were excluded because they were prospective MIE-ACT presenters rather than current presenters. Of the 20 remaining eligible participants, 10 were selected for further analysis on the following basis: (1) only females were selected; (2) saturation, when new sources of data were not extending information but merely confirming specific coding (Marks & Yardley, 2004), was reached at nine interviews—at this stage further data only 'adds bulk to the coded data and nothing new to the theory' (Glaser & Strauss, 1967, p. 111); (3) 10 cases is sufficient to provide a detailed analysis that examines the similarities and differences among cases, without being overwhelmed by the amount of data

generated (Marks & Yardley, 2004); and (4) these 10 interviews provided a good cross section of presenters on the criteria of age, diagnosis, length of time since diagnosis, length of time presenting, and the interviews had been conducted by several different interviewers (to reduce interview bias).

A semi-structured interview schedule was designed to explore the potential positives and negatives for consumer educators. Questions were developed in consultation with a working party comprising mental health consumer and carer educators, MIE-ACT staff and representatives from the ACT Mental Health Policy Unit. Such a collaborative approach is consistent with the ethical standards for research with mental health consumers (Peterson, 1999). The interview questions investigated the reasons for becoming and remaining a MIE-ACT presenter and the impact of being a presenter on the participants' lives. Two pilot interviews were undertaken to refine questions before the main interview phase was conducted. The questions were designed to be open-ended and non-leading, such as, 'What benefits have you gained from being a presenter?', 'What drawbacks or disadvantages are there to being a presenter?', and 'In what ways, if any, do you feel that being a MIE-ACT presenter and educator affects your personal recovery?'

The interviews were conducted by three interviewers: two females and a male and usually took about one hour to complete. Digital audio recorders were used with permission; interviews were fully transcribed and participants were given the option to review and amend their transcript.

Analysis

Transcripts were analysed using a thematic analysis approach, which is a method for identifying, analysing and reporting patterns (themes) within data (Braun & Clarke, 2006). Thematic analysis involves a 'system of coding text into theoretically defined categories using a systemic approach' (Silverman, 2000, p. 377). In thematic analysis, a theme can refer to the manifest content of the data—that is, something directly observable, such as mention of 'stigma' in a series of transcripts—as well as examining text for elaborated statements and coding at the

latent level; for example, talk in which stigma is implicitly referred to. Thus, interpretation of the meaning of the text is required in this approach (Marks & Yardley, 2004).

Data were analysed using Miles and Huberman's (1994) reiterative comparative procedure. This method repeatedly examines interviews for commonalities of theme or emphasis across narratives and will reveal both differences between participants and commonalities concerning dominant themes. Initial analysis was done by hand, followed by use of NVivo 7.

Two tests of coding reliability were conducted. To test coding consistency over time, a week after initial coding, the same coder re-coded three clean (uncoded) transcripts (Richards, 2005). Analysis compared initial coding assignment to coding assignment a week later. To test inter-rater reliability, the stronger indicator of reliability (Joffe & Yardley, 2004), three clean transcripts were coded by a second independent coder. Coding assignment was compared between the two independent coders. Cohen's Kappa coefficient corrects for the number of agreements that would occur by chance between coders and was .87; Kappas of .75 and above are considered excellent (Robson, 2002).

To determine the level of endorsement of responses, three levels of nomenclature were applied, as proposed by Hill, Thompson and Williams (1997): a theme that applies to all the cases is *general*; to half or more of the cases is *typical*; and to less than half of the cases is considered *variant*.

Results

While all the participants identified both positives and negatives of being a consumer educator, the positives (229 references) far outweighed the negatives (37 references) across the 10 interviews. Four main themes emerged for the positive elements of presenting: the unique peer support and encouragement provided by other presenters; the personal meaning gained from educating others about mental illness; the benefits of validation and catharsis through telling their story; and the skills gained through embarking on their role as a consumer educator. Negatives included feeling vulnerable or 'raw' during or after presentations, feeling fearful of being stigmatised, and facing challenges with co-presenters. Figure 1 presents a concept map, which pictorially depicts the themes, their relative strength (size of the concept), and the inter-relationships.

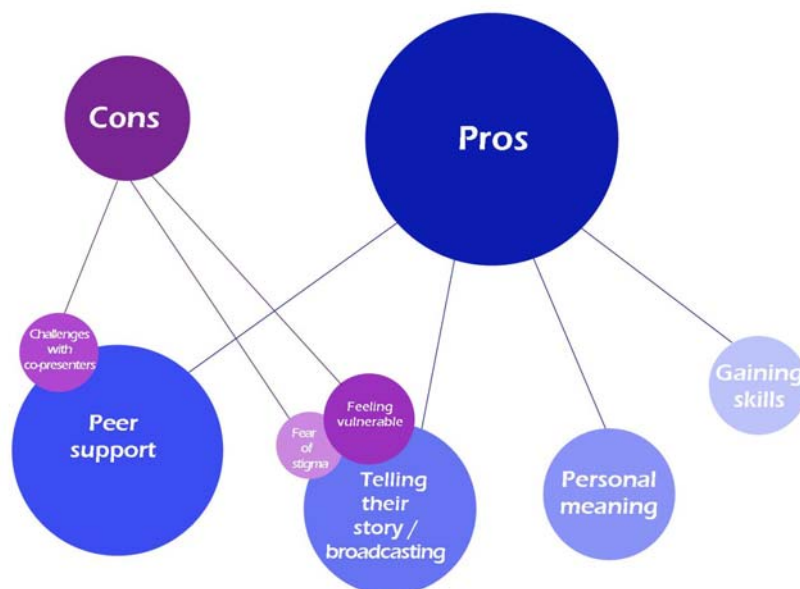


Figure 1. Concept map: Positives (pros) and negatives (cons) identified for recovery

The first major benefit identified, peer support, was general—a positive for all 10 participants. Participants reported experiencing a unique bond with other presenters, due to a sense of shared understanding and experience, and genuine acceptance amongst the group.

'There is a sort of common bond I'd have to say. There is a sort of sense of community. I feel like I belong in MIE-ACT. It's like finding your tribe a little bit.'

'I think it was partly ... being part of a community with people was very healing. So where there was no stigma and where mental illness was spoken about in a very positive and very loving way and a very kind and compassionate way. That was very healing to be around people where I wasn't judged.'

All participants also talked about the value of gaining personal meaning through educating others. Three components within this theme became apparent: helping others; reducing stigma; and prevention.

All presenters stated that one of the main reasons that they decided to become a presenter was to use their experience of mental illness to help others.

'I guess I feel I'm glad if I'm doing something that might affect the life of even one person. I guess that makes you feel that you're making some sort of contribution to the world. And if these kids can benefit later on from it then that makes me feel better about myself.'

Nine participants noted that providing education to students to reduce the stigma of mental illness gave them a sense of personal meaning.

'That's what we're really trying to achieve in teaching about stigma in the community, saying we're all the same – mental illness, physical illness is the same. It's just an illness. I'm just a person. This is my life experience.'

Seven participants noted that having been through difficult experiences of their own as mental health consumers made them even more passionate about providing education so that others will not face the same struggles they have.

'I want to give kids the message that this is a really common problem – to have a mental illness – and that really the only way to deal with it is to actually get help ... I want to encourage people to share their problems and to actually deal with it because I didn't do that. I guess I don't want people to have to suffer

the same that I did when I was younger. It's a really personal experience for me to have to deal with young people and to help them.'

Another general theme was the personal benefits of telling their story. Three main components to the storytelling process were revealed: feeling a sense of catharsis; feeling validated; and feeling their sense of self-confidence grow.

Nine participants noted that one of the positive aspects of telling their story was that it was healing and therapeutic to 'get it out there in the open' and it helped them reflect back and see how far they had come along their path of recovery.

'I think there's something very healing about publicly identifying with a mental illness.'

'I guess as I become more confident and become more distant from my own illness ... It's shifted for me from being at the start more of a catharsis and dealing with that. But it's really shifted for me to being something that – it's almost not as personal anymore.'

Every participant talked about experiencing feelings of validation when they told their personal story in schools. Many talked about the fact that they had never shared their story publicly before and that although they were initially fearful of doing so, the validation from students and co-presenters made the process invaluable.

'I think they appreciate the presenter's honesty in just telling it how it was and not pretending about anything. They always become silent immediately the personal stories start and you can hear a pin drop usually. Even the ones who've been mumbling up the back stop and listen, and that's partly courtesy I expect but they know that you're spilling your guts out so they do recognise that it's time to stop talking.'

Nine participants reported that their confidence had grown through the process of telling their story publicly and having it validated, and that they had noticed the same process occurring for other MIE-ACT consumer educators as well.

'I guess one of the things that I love about MIE-ACT and this is not to promote MIE-ACT, but what I've seen is people have come where they've felt very shaky and vulnerable but been willing and courageous enough to share their personal story and got to a point of feeling good and confident. They've actually gone on in life then and some people have

gone to uni to study psychology, other people now hold positions in the mental health arena as experts on their personal story about mental illness and stuff and I just see that as really valuable.'

Another general positive theme was the skills gained by being a MIE-ACT consumer educator that could be applied in other areas of life. Participants talked about feeling more confident in public speaking arenas and noted that this new skill gave them confidence to develop talents in other areas of their life.

'Being a presenter and then moving on to a trainer – it's then a whole new skill set which has just been fantastic, which I'm using in different areas now. And that's been great.'

Several negatives or costs related to volunteering as a consumer educator were also acknowledged by the participants, however. A typical theme, reported by eight participants, was that feeling vulnerable was a potential drawback of telling their story. Presenters described feeling 'exposed' or 'raw' after presenting, and some noted that it left them feeling quite down for a period of time afterwards—reflecting on what they had been through and the fact that they had shared such intimate details with strangers.

'Sometimes afterwards you can feel a bit – oh, I can't think of the right word for it, but you sort of feel a little bit exposed. Like you maybe have said a bit more than you thought you were going to say and stuff.'

Five participants talked about the fear of stigmatisation that they sometimes felt when presenting. Although these fears had not been realised, the fear of stigmatisation within the community as a result of disclosing was still a potential threat.

'Sometimes I think it's more the ramifications of having shared if it's going to have an impact on you with respect to your job. And it still happens. It doesn't happen a lot but I mean people can see you in a different light. Oh, she's the one with the mental illness instead of oh, that's such and such. Or people are waiting for you to crash because you've got that mental illness.'

Five participants also noted that one of the drawbacks of being a consumer educator was managing challenges with their co-presenter. Concerns identified were about co-presenters wanting to present in a different style and co-presenters being unwell during presentations and

the potential consequences of this (such as reinforcing negative stereotypes of mental illness to the audience). While these concerns were not directly related to their own recovery, they impacted on how well the consumer educators thought the anti-stigma messages were being conveyed and were a potential source of stress related to presenting.

'There was one incident I suppose where I had a co-presenter come who was unwell, exceptionally unwell. And what to do about that was very challenging.'

Discussion

Interviews with these 10 consumer educators revealed that volunteering as a MIE-ACT presenter clearly supported recovery for these women. The principal theme that emerged was the value of peer support. All presenters talked about feeling a unique sense of acceptance and understanding from other presenters through a 'shared bond' with the group. Interestingly, providing peer support is not an objective of the MIE-ACT program, but a benefit that occurs incidentally. Peer support has been identified across the literature as an important factor in working towards recovery (Solomon, 2004).

Another general theme reported by all participants was a strong sense of personal meaning gained through educating others. The women felt educating others was valuable because it helped young people increase their understanding of mental illness and early warning signs, reduced stigma, and was preventative by providing information on where to get help early. Finding personal meaning is a strong theme in first person recovery literature (Crossley, 2000). Research has shown that mental health consumers often have to re-assess their life goals and aims (Mead et al., 2001), and that many strive to find meaning in their illness (Roe & Chopra, 2003). Results from the current study provide further support that setting new life goals and finding ways to achieve them that are in line with the consumer's core values are paramount in achieving a sense of personal meaning. Many consumer educators in the current study expressed a strong sense of personal satisfaction in going into school settings and educating others—it gave them a life purpose and a strong sense of personal meaning.

The consumer educators experienced several benefits as a result of broadcasting—telling their story in a public forum. Some talked about the direct impact of telling and re-telling their story and the therapeutic effect that this had for them in reducing self-stigma and assisting in positive identity development, consistent with findings reported by Lapsley et al. (2002). Feelings of catharsis and validation were noted as powerful mechanisms in moving towards a more positive identity. A typical theme was feeling a sense of empowerment over the stigma and illness when presenting. This is consistent with research by Corrigan and Matthews (2003) showing that ‘coming out’ publicly can serve as a type of catharsis and creates a sense of power over the experience of mental illness and the stigma associated with it.

In contrast to these benefits of storytelling and broadcasting, one of the few negatives that emerged was feeling ‘raw’ or vulnerable during or after presenting. This shows that adequate supports must be put in place for consumers who choose such advocacy roles, and that it is neither appropriate for all consumers nor for consumers at all stages of recovery. Careful screening of potential volunteers is essential, as well as appropriate initial and ongoing training and support, and debriefing. Furthermore, half of the participants noted that fear of being stigmatised as a result of presenting was an ongoing concern for them. While none had experienced actual discrimination, it remained a real fear. Again, a high level of support is indicated to ensure the wellbeing of the volunteers.

Finally, consumer educators identified feeling that they had gained a range of skills that had contributed to their self-confidence. A typical response was that public speaking skills had improved dramatically as a result of volunteering in this advocacy role, and that this had a more generalised effect whereby it gave them confidence to develop new skills in other areas of life. These findings are congruent with research by Schiff (2004) who found that recovery involves being able to use one’s gifts and talents. The positives that emerged as a result of volunteering as a consumer educator were consistent with the main themes found in the recovery literature—that recovery involves being able to help oneself and others, acceptance of

self, gaining confidence, taking responsibility, living with hope, and making connections with others (Schiff, 2004).

Several limitations of the research should be noted, however. Clearly, the study brings with it the limitations of qualitative research. In particular, the researchers’ biases when interpreting the data must be acknowledged, and the lack of precision that qualitative methods encompass (Carley, 1993). In addition, the findings of the research cannot be generalised to the consumer population due to the highly selected and small sample size. Notably, the study consisted of female participants only, and future research should investigate possible gender differences.

Nevertheless, the findings from this study suggest clear benefits for these consumer educators in telling and re-telling their stories, and for ‘coming out’ in a public forum. This is one of the first studies to demonstrate these findings; further research is required to confirm them, as there is a paucity of research literature surrounding storytelling and broadcasting. Furthermore, research examining other ways in which consumers can engage in similar storytelling processes—without the risks associated with broadcasting—may be of benefit for others on their recovery journey. For example, consumer support groups could consider the role of storytelling when developing their group processes, as these groups comprise a ‘safer’, less public way to disclose. Findings regarding peer support, personal growth and gaining skills concur with previous recovery research, reinforcing that such processes should be incorporated in aftercare to assist with mental health recovery.

In terms of better understanding of advocacy roles in the mental health field, it is unknown whether the effects of this type of advocacy role through MIE-ACT are similar to those of other advocacy and consumer roles, and further investigation is needed. The effects may be due to unique characteristics of MIE-ACT, such as individual staff characteristics and types of support. Future research examining other advocacy organisations would be useful to determine whether the outcomes of this study are more widely supported.

In conclusion, this study has provided one of the first explorations of the impact of a consumer advocacy role on mental health recovery. It reveals that volunteering as a consumer educator can promote mental health recovery through the unique social support experienced with peers, the personal meaning attained through educating others, the re-self-defining nature of storytelling and broadcasting, and gaining new skills that can be applied in other areas of life. While some drawbacks were also inherent in the role, the positives clearly outweighed the negatives, and this advocacy role was experienced as a valuable part of the recovery journey.

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