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ARTICLE

Mental Illness Education through Stories of Lived Experience: Validation Review of the DoNOHarm Framework

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ABSTRACT

The lived experience of people with mental illness is a powerful way to promote mental health literacy and reduce the stigma associated with mental illness. However, there is little guidance on how to do this safely. Mental Illness Education ACT is an Australian organisation that since 1993 has supported volunteer educators to share their individual stories of lived experience to school and community groups. In 2011, they developed the DoNOHarm Framework to assist volunteers to be able to talk about their experiences in a way that is safe for them and for their audience, a gap that they recognised in the field. This study reports a review of the Framework, considering the extent to which it is supported by the current literature and how it is being implemented and experienced by the volunteer educators. These research questions were addressed by a literature review and interviews with 14 volunteer educators and the staff that support them. The review of published literature over the past 10 years showed strong evidence for three of the six principles of the Framework: Context and Purpose, Recovery Emphasis, and Safe Talking. Although the principle of Respectful and Inclusive Language is widely promoted in the mental health field, no recent studies investigated the benefits of this approach. Similarly, there was no recent research into the two principles of Limits to Helping and Self Care. The interviews revealed strong support for the Framework among volunteers. It was seen to be effective to protect the safety of both presenter and audience, ensure the relevance of the presentation, give educators confidence in their message and delivery, convey a hopeful message, and make certain that presentations were engaging for the audience. Overall, this review shows that the DoNOHarm Framework fills an important gap for mental health education, with a sound evidence base where there is published evidence available.

KEYWORDS

Mental illness education; lived experience; storytelling; harm; safety framework

1 Introduction

Educating about mental illness is an essential component of mental health promotion. Education programs, including those conducted in schools and large-scale community campaigns, can be effective at reducing the stigma associated with mental illness, improving mental health literacy, and improving help-seeking intentions [1,2]. In secondary and tertiary education settings, programs have been shown to have a positive impact on participants' understanding of mental illness and the concept of recovery [3–5].

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Similarly, programs presented in workplaces are effective in bringing about changes in stigma and attitudes to help-seeking [6].

Mental Illness Education ACT (MIEACT) is an organisation that has been operating to promote mental health literacy and reduce the stigma of mental illness in the ACT region in Australia since 1993. MIEACT has volunteer educators present mental illness education seminars in schools, workplaces, and with community groups. The volunteers share their individual stories of lived experience to educate people about mental illness and the pathways to recovery. The story that an educator shares is a powerful method to convey the experience of mental illness [7]. For example, in a large study in high school settings, many students were deeply touched by personal stories, which made the impact of mental illness tangible and encouraged the realisation that people with mental illness were just 'ordinary people with extraordinary stories' [8]. Similarly, a qualitative study found that nursing students who heard stories of presenters with lived experience were able to see beyond the diagnosis, to see the actual person [9].

Telling their story as a mental illness volunteer educator can have many benefits for presenters, including a role in their recovery journey for those who are suited to being an educator. However, such storytelling is not without risks. For example, a typical theme reported from qualitative research with volunteers was feeling 'exposed' or 'raw' after presenting, with some interviewees noting that they felt quite down for a period of time after presenting due to reflecting on what they had been through and the fact that they had shared such intimate details with strangers [10].

Having people with lived experience tell their stories to help educate others is increasingly promoted as a way to highlight awareness of a number of personally sensitive issues, including family violence, sexual assault, and suicide, as well as for mental illness. Yet there is little guidance on how to do this safely, without re-traumatising the storyteller, or triggering or overly upsetting any audience members. Mental illness education needs to be a safe, positive, and effective experience for both presenters and audience alike. Appropriate preparation and support are particularly important aspects to consider when providing mental health education presented by people with lived experience [7].

1.1 DoNOHarm Framework

MIEACT developed the DoNOHarm Framework in 2011 based on their experience delivering mental illness education sessions presented by people with lived experience, and on research evidence supporting this approach [11]. The Framework provides presenters who have personal experience of having a mental health problem or of being a carer or family member of someone with a mental health problem with a process to guide and support them in their communications about their lived experience. The Framework is the basis of training and ongoing support for volunteer educators, and focusses on both the development and delivery of their story.

The primary aim of the Framework is for volunteers to be able to talk about their experiences in a way that is safe for them and for their audience. It supports volunteers to be able to confidently talk about their illness, emphasising the importance of inclusive and safe language that promotes respect for people living with a mental illness, and reducing the risk of secondary trauma for the audience.

There are six guiding principles underpinning the DoNOHarm Framework [12]:

- Context and Purpose–Understand how we talk about mental health experiences for the purposes of education and awareness to minimise emotional distress
- Recovery Emphasis–Focus on a positive outcome that builds on help-seeking behaviour, self-determination, and the promotion of hope
- Safe Talking–An evidence-informed guide to language choices on sensitive subjects across the mental health spectrum

- Limits to Helping–Understand your role within a mental health space, assess own capacity, and give yourself permission to set boundaries to helping
- Respectful and Inclusive Language–Understand how to build a mentally healthy culture and remove barriers that generate stigma
- Self Care–A sustainable approach to establishing and maintaining personal wellbeing when sharing or hearing stories.

1.2 The Current Study

Although evidence-informed based on the literature, 25 years of practice, and external evaluations, MIEACT wanted to undertake a rigorous, external validation check of the DoNOHarm Framework. The organisation therefore commissioned external, independent researchers from the University of Canberra to undertake a validation review of the Framework in late 2020.

This study reports that review, which considered two main research questions:

1. To what extent is the DoNOHarm Framework supported by the current literature?
2. How is the Framework implemented and experienced by the volunteer educators?

2 Methods

Two methodologies were used to address the research questions. These were 1) review of the literature that relates to and underpins the DoNOHarm Framework, and 2) interviews with volunteer educators and the staff who support them to determine how they are implementing and experiencing the Framework.

2.1 Review of the Literature

A search of the literature was conducted to identify studies that examined factors relevant to the DoNOHarm Framework. All searches included the keyword 'mental' AND 'story*' OR 'narrative'. Specific keywords relating to each of the six guiding principles were:

- Context and Purpose-'education' 'audience' 'consumer' 'carer' 'lived experience' 'contact-based'
- Recovery Emphasis-'recovery' 'help-seeking' 'self-determination' 'hope' 'restorative narrative' 'recovery journey'
- Safe Talking-'referred trauma' 'trigger' 'vicarious trauma' 'negative narrative' 'secondary trauma'
- Limits to Helping-'boundaries' 'limits'
- Respectful and Inclusive Language-'language' 'person-centred' 'outgroup' 'non-judgmental'
- Self Care-'monitoring' 'self care' 'self-management' 'self-monitoring' 'inner narrative'.

Searches were limited to peer-reviewed studies published in the English language over the past 10 years, between January 2011 and October 2020. Studies using any research methodology were included. Although the focus of the Framework is on the preparation and delivery of mental illness education sessions, studies were also included if they had a focus on mental health promotion, mental health literacy, or mental health awareness.

Searches were performed in the Medline, PsycINFO, JSTOR, and CINAHL databases, entering combinations of keywords into the Subject and Abstract search fields to identify potentially relevant articles. For each search, the titles of the articles were screened to identify articles that referred to factors related to the Framework guiding principles. The abstract of articles that were potentially relevant were then accessed, and the full text of the article sourced if the content of the article was relevant.

A systematic review was originally contemplated, but we realised after initial attempts that the relevant literature was very diverse with multiple terms required to cover the entire Framework, as evident in the final

keywords used. Consequently, while the general methodology of a systematic review was implemented, a narrative review conveying the key literature related to each Framework principle is presented.

2.2 Interviews with Volunteer Educators

2.2.1 Participants

All volunteer educators (VEs) working for MIEACT (n = 20) and staff (n = 3) involved in the volunteer education program at the time of recruitment (October 2020) were invited to participate in this research. Potential participants were informed via an email sent by MIEACT. Those who expressed interest were sent an information sheet and a consent form. Those who agreed to participate informed the volunteer coordinator at MIEACT and returned their consent form. Participants were then scheduled an interview time, and their name, email address, and preferred time were provided to the research team.

Altogether, there were 14 participants, 12 VEs and 2 staff who were interviewed in November 2020. The VEs were 8 women, ranging in age from 19 to 53 years (mean = 37 years) and 4 men, ranging in age from 32 years to early 70's (mean = 56 years). The average length of volunteer service was 2.8 years (range 2 months to 12 years). There were 7 participants who had been with MIEACT for between 2–12 years and were experienced presenters, and 5 who had commenced their DoNOHarm training and had either not yet written their story or had not yet presented their story. Participants had a variety of lived experiences of severe mental illness, including bipolar disorder, schizophrenia, major depressive disorder, anxiety disorder, and eating disorder. One participant was a carer. The length of their experience living with a mental illness also varied between 5 and 40 years.

2.2.2 Procedure

A semi-structured interview approach was used to investigate participants' perceptions of the DoNOHarm Framework and how they apply the Framework in their work with MIEACT. This method was chosen as it elicits participants' views through pre-designed interview questions, based on the research questions, that guide the conversations between the interviewer and interviewees within the range of research interest [13]. The semi-structured interview format allows researchers to have flexibility during the interview, to request more information, clarify details, and explore new information in more detail [14]. Due to COVID-19 and the uncertainty around changing restrictions, interviews were conducted online via Zoom. This format allowed for audio and video recording. Participants were asked to give their consent to be recorded prior to the commencement of the interview (all participants gave consent) and were offered a copy of their transcribed interview. Interviews ranged from 22–58 min, with an average of 38 min.

Ethics approval was obtained from the University of Canberra Human Research Ethics Committee (Project 5823).

2.2.3 Analysis of Interview Data

The interview data were thematically analysed, as this is a flexible method used to search for meaning in qualitative data by locating themes embedded in the data that depict the perceptions and experiences of participants. We used the six-step procedure proposed by Braun et al. [15]: becoming familiar with the data, generating initial codes, searching for themes, reviewing the themes, defining and naming the themes, and reporting the results. NVivo 12 software was used to transcribe the interviews and conduct the analysis.

Transcriptions were read and checked for accuracy, against the audio recordings when necessary, ensuring that the intended meaning of the respondents was clear (KT). Throughout this process, the aim was to become familiar with each whole transcript, noticing ideas that were repeated throughout each individual interview, and developing a sense of the overall perspective of the participant and any particular points they emphasised.

The coding was data-driven, although this was naturally strongly aligned with the specific guiding research questions. Focussing on three aspects to guide the coding process is recommended: the information provided in the data, the research questions, and whether and how the information will be used for answering the research questions [16].

The identification of themes was data-driven after all interview data had been coded. Some themes were only supported by one or two participants; however, these themes were retained because of the small sample size and the intention to provide a voice for all the participants and gain as much insight as possible into how the Framework is experienced and used. The identification of themes took place over several repetitions, with the data contained in each code closely examined to ensure no new information was missed. Following the initial coding process, the codes were re-examined to make sure that they represented the data well, with all three researchers (KT, DR, PB) agreeing on the coding to reach consensus regarding the themes.

3 Results

3.1 Overarching Framework

The review found no studies that focused on the six principles of the DoNOHarm Framework, but revealed two studies identifying the key ingredients of anti-stigma and mental health education programs and one conceptual framework of the characteristics of mental health narratives, which aligned closely with the Framework. Corrigan and colleagues identified key factors in the delivery of effective contact-based mental health promotion programs, highlighting the importance of program presenters having lived experience, face-to-face delivery of programs, structured training for program presenters, an 'on-the-way-up' story, a message emphasising an empowered person who attains goals, and a message that is respectful of and relevant to the target group [17,18]. Knaak et al. [19] identified seven key ingredients for anti-stigma programs for use with health care providers: personal testimony by a person with lived experience, social contact with persons with lived experience, focus on behavioural change, myth-busting, enthusiastic facilitator, recovery emphasis, and booster sessions. A review of 45 studies revealed the effective characteristics of mental health recovery narratives to be related to the form, structure, and content of the narrative, and prioritising recovery [20].

Several guides have been developed to support people with lived experience as they prepare and present their story, and a selection of these is presented in Appendix 1. These highlight the importance of promoting a recovery focus, to use respectful language, and to consider the audience in the preparation and delivery of the story.

Interview participants shared their understanding of the DoNOHarm Framework, noting it was designed to keep themselves and their audience safe when they share their lived experience, '*Basically, it just creates a safe environment for everyone involved during a presentation'. (Experienced VE)*

Several experienced VEs and staff discussed the Framework from a historical perspective, explaining that there was a need to have clear guidelines in place to ensure that the audience did not experience trauma from the presentation and that presenters did not experience any negative effects from retelling their story.

They had identified that there were some risks around the way that people were sharing their stories, without any sort of guidance about what might be ... unsafe in terms of language or in terms of the experiences people shared. So, in the first instance, it was a storytelling Framework and it was targeted at a very risk-based model where the stories are being told to young people in schools. But it expanded beyond that because it became quite clear that it was a useful Framework ... more broadly. (Experienced VE)

More experienced educators talked about the overarching aim of the Framework being to convey their message clearly, but in a way that did not upset anyone in the room.

That's the core of it and that's what I always keep in mind, don't upset the others [presenters] and don't upset yourself, or the audience, or the teacher in the room. (Experienced VE)

To me, what it's all about is basically being able to safely get your message across, get your story across, the key points, without frightening people or bringing out things which are quite distressing and also in the choice of language. (Experienced VE)

Staff offered a more functional value for the Framework, pointing to its usefulness guiding discussion on mental health topics in a range of different contexts, not just in the presentation of stories of lived experience.

I think for me, the DoNOHarm Framework is essentially six principles that guide the way we talk about mental illness, how we discuss mental illness or mental health … in order to reduce potential triggers, increase safety, increase help-seeking, and … [the Framework] helps give confidence to conversations and also helps us for responding to situations of disclosure. (Staff member)

New volunteers discussed the overall purpose in terms of the safety the Framework provides volunteers and the audience.

I guess to avoid triggering ourselves or triggering people in the audience … and we make sure we have the right context for our audience. (New VE)

3.2 Core Principle: Context and Purpose

As highlighted in the work of Corrigan and colleagues (2012, 2013, 2014), the context and purpose of a program is interwoven into the key ingredients of anti-stigma and mental illness education programs. Aspects of *Program Design* that focus on the appropriateness of the presentation to context and purpose include face-to-face presentations in the setting of the target audience. Aspects of the *Targeting* component include the presentation being aligned with the target's goal, that a specific group is identified, and that a partnered plan is developed with representatives of the target group. In the *Messaging* component, it is important that the message presented is respectful to the participants in the target group and relevant to the diversity in that group. Importantly, a large meta-analysis of 101 studies that examined the comparative effectiveness of contact-based education sessions on reducing stigma found no difference in the effectiveness of presentations from people with a particular mental illness [21].

All the interview participants talked enthusiastically about the principle of Context and Purpose, with many mentioning that this was one of the most important elements of the Framework, important for both crafting their story and presenting it. The themes that emerged were safety and relevance to the current audience.

Purpose and context, which I think is … absolutely fundamental and I think it's probably the one I take into consideration the most when I'm telling my story, "What's my purpose here, what's the context, who is my audience", that kind of thing. (Experienced VE)

I actually write every time I get an audience, I go to my story and I review it and I don't rewrite it from scratch obviously, but I do tweak it for every single audience. (Experienced VE)

Some presenters reflected on the different audiences they present to, noting, for example, the need to educate school audiences more broadly on mental health topics, but that for presentations to professional audiences, such as to the police, there was the opportunity to talk more about their experiences with mental illness.

I also do the federal police. … Obviously the context and the purpose there is vastly different from the context and the purpose of talking to Year 10 students in a school, so you can be far more direct or explicit and use more clear language when you're talking to the police, and you can give concrete examples when you're talking to the police, because they've seen it or they're going to see it, so the context and purpose is most helpful for me. (Experienced VE)

New volunteers frequently commented on the value of spending time thinking through the context of their presentation and the purpose for their audience, and how the Framework gives them a way to protect themselves and the audience.

The other stuff for me goes around the context, if you just have the context in your head first, it really sets you up to have a very safe experience and probably a really constructive one, because you are thinking about the purpose, you're not thinking about how they're going to react or how am I going to feel. You come back to this idea of purpose. And I think that's really useful and very grounding for everybody. (New VE)

One staff member also saw the purpose of the Context and Purpose principle as another mechanism that helped to keep volunteers safe.

Someone has the ability to say, "No, actually, I don't know I can tell this because I'm not sure today. So, actually today, I won't go into that bit because I don't want to talk about that part". And I love this, because then the volunteers say, but that's okay, because that comes back to context and purpose. (Staff member)

3.3 Core Principle: Recovery Emphasis

A recovery message is a key ingredient of effective contact-based programs and including narratives of 'on-the-way-up' stories (Corrigan et al. [17]). Restorative narratives that promote hope and resilience have been found to be more effective at influencing prosocial behaviour, compared to negative narratives that focus on the suffering and challenges associated with a mental illness [22]. The positive message of restorative narratives can be beneficial for listeners, as the content of the story can be distressing for people, and hearing about the hope and positive outcomes of the presenter can draw people into the experience. A review of contact-based education programs aimed at young people in Canada found that the most effective storytellers had a recovery message and did not share long accounts of the signs and symptoms associated with their illness [2].

A qualitative study of the experiences of Finnish 'experts by experience' presenters explored how the concept of recovery shaped the stories of the presenters [23]. Analysis of the interviews revealed that presenting had positive outcomes for the individual, as it allowed them to reconstruct their own story beyond their personal recovery, to incorporate a focus on influencing societal attitude change. Presenters explained how they needed to step back, or distance themselves, from their story of their embodied experiences, in order to provide a description of their experience in a way that their audience could understand.

In the interviews, the importance of presenting stories with a recovery emphasis was discussed by two experienced volunteers, four new volunteers, and both staff members. For new volunteers, the message of hope in their stories was important.

That focus on positivity and recovery, and that's really good for the storyteller to be reinforcing their own agency in their own recovery, and it's also, I think, really good for the listener too. So, that gives them those examples of recovery, and that it is something that people work hard at. (New VE)

For staff, a message emphasising hope and recovery was thought to be more likely to connect with the audience and encourage listeners to seek help.

We do see that when we use that recovery and hope-based language and outlook and perspective, is that people will connect to the message. You can sit there and you talk about mental illness and all the dark parts, or, you can talk about where you're at now, so that people aren't scared to say actually, maybe, some of that resonated in my own experience, but I don't want to get help because I don't want a mental illness. If that's going to look more like my story, okay, maybe I can get help. (Staff member)

3.4 Core Principle: Safe Talking

Emotionally descriptive language in presentations can promote empathy and a connection between the presenter and the hearer, however, some recipients of the message can be left feeling vulnerable and experiencing distressing emotions because of parallels with the hearer's own experience [24]. In developing their conceptual framework on the impact of recovery narratives on the audience, Rennick-Egglestone et al. [20,24] identified two areas that are particularly relevant to the Safe talk principle:

eating disorders and secondary trauma. The response of some people after hearing narratives presented by people with an eating disorder is an increase in eating disorder behaviours, with particular risk points being narratives that have sufficient detail to allow copying of the eating disorder behaviour, that trigger previous behaviours, and that contain unhelpful social comparisons with the narrator. In terms of secondary trauma, exposure to some narratives can cause distress to the listener.

In the interviews, this principle was discussed more often than any other. Volunteers reported using language that will not scare listeners, trigger a past memory, trigger self or the audience, provide details of attempts to take own life, name specific medications, normalise or glamorise suicide, and that will avoid copying behaviour.

There's always two ways to tell the story … there's a good way and a bad way to say it. (Experienced VE)

The Safe talking … were the bits where I learnt the most in the training. How do you speak about suicide in a way that's safe? … Committing suicide, that is so hard to remove from our language, you know. (Experienced VE)

For some new and experienced volunteer presenters, following this principle gave them permission to not speak about some parts of their story to some audiences.

Once upon a time, I thought "Oh, I've got to explain that". But now I know I don't have to explain that, it's okay to just use the generalisation … I no longer give any examples because it's not necessary, it's just good enough to say inappropriate actions and behaviours and high risk behaviours. So, I used to give examples of high-risk behaviour, now I just say high risk. (Experienced VE)

The main challenges volunteers mentioned regarding the Safe talking principle were responding to questions from the audience, presenting sessions that went for longer than the presentation they had prepared, saying something that on reflection they regretted, and softening the language in their story so that it wasn't quite as real.

When you do a 20-minute talk, you open it up or you get more questions … Some people do get a question where they request more information about something and it's difficult for the presenter to determine how much do I now give and how much do I not give and, quite frankly, I just say, "I don't answer that question, look, that's something I don't want to talk about", or "I don't want to go into that". (Experienced VE)

I felt at the beginning that I wasn't sort of portraying myself, because I wanted to be really real and tell it exactly how hard it was, but I just eventually had to learn that maybe softening the language of it is what's best for some audiences, and that's what I found hard. (New VE)

Some experienced participants noted how knowledge of the Framework could not always protect them from experiencing potential harm themselves when giving a presentation.

The DoNOHarm Framework doesn't really teach you how to adapt things on the fly … then what I've seen happen is a bit of safety creep, and that often happens when people go in unprepared and go off-script, there's a risk that they'll over-share. (Experienced VE)

3.5 Core Principle: Limits to Helping

No studies were identified that examined the importance of limiting the help that presenters offer or provide directly to others. This principle was also not evident in the key ingredients of contact-based programs. It is possible that the need to set boundaries about how much care and support an individual can provide others is incorporated more broadly in the literature on self-care for helping professions, rather than it being a distinct category within the context of mental health education. However, it is an important distinction for volunteer presenters of lived experience, as they are not professional health carers.

In the interviews, safety was the one theme that summed up participants' discussion of this principle. The Limits to Helping principle was noted to set a boundary for volunteers, defining their role as an educator and not as a trained mental health worker. All experienced volunteers discussed the importance of this principle when giving presentations, in particular, not becoming involved with members of the audience who come and talk to them after a presentation. Many presenters explained that in their role as a professional storyteller they need to refer people to appropriate help, which in the school setting often meant encouraging students to talk with their teacher.

We're not advice givers, we're storytellers. (Experienced VE)

The thing we do now is just refer ... If we keep that in mind, that all we can do is refer and leave it at that, and for your own sake, walk away, because you can't do anything about it. (Experienced VE)

You're not a counsellor or a mental health practitioner. (New VE)

New volunteers also talked about how they found this principle to be useful in other aspects of their life, for example, in their relationships with family. It helped them to tell others that they were not the right person to help them and that they needed to seek professional support.

I quite like the Limits to helping, because some of my friends and my family, I'm pretty sure they have some mental health problems, but they don't go to the counsellor, instead they will talk to [me], and it's quite stressful. (New VE)

Staff members also reinforced the importance of knowing the limits that volunteers have when helping other people, and that this is one way that MIEACT can help to keep volunteers safe in their role as educators.

My role is to elicit that awareness and the emotions around that, and that's my end point. So, it's great that it has elicited something, but it's not my role to fix anything that comes out of it. Essentially, it makes [volunteer educators] feel safe going in there, because they're not expected to counsel somebody ... in their situation. (Staff member)

3.6 Core Principle: Respectful and Inclusive Language

While there is a strong advocacy to address the stigmatising language that is often used to describe mental illness or people with a mental health problem, there is little recent research evidence that examines the impact of using respectful, inclusive, or person-first language. Only one of the studies investigating the key ingredients of anti-stigma programs highlighted the importance of presenters having an enthusiastic person-centred approach when delivering contact-based programs [19], which can be assumed to include the use of respectful and inclusive language. The one study that examined the effect of language choice used in vignettes shown to mental health workers did not find any difference in participants' attitudes across the different language styles [25].

Nevertheless, the use of person-first language that speaks of the person before the illness is promoted in the mental health field and is closely linked to the recovery movement, promoting respect for the individual and conveying hope. Person-first language sets an inclusive tone; it influences change in community attitudes and is a positive guide for people who are recovering [26]. Appendix 1 presents a selection of guides that are available that promote person-first language.

In the interviews, Respectful and Inclusive Language was the principle that was talked about the least by volunteers, with only three experienced VEs and one new VE discussing the influence of this principle on the way they prepare and present their story. Some educators talked about this principle being the one they find most difficult to apply. They also discussed how it can be a challenge to ensure the language they use in their presentations is appropriate, particularly when responding to questions from the audience that they are not prepared for. Volunteers considered how many words and phrases commonly used are not respectful,

such as ‘crazy’, and that they need to remain vigilant with their language and ensure they avoid the use of these terms. The themes of safety and relevance were evident when participants talked about this principle.

I think the one that poses the biggest problem is Respectful and inclusive language, because there’s so much loose language in society, and we even do it ourselves. (Experienced VE)

The new VEs emphasised the importance of language from the perspective of some language being offensive to other people, and that avoiding this language helps to protect the audience.

Staff members also discussed the importance of ensuring that language used is respectful and inclusive and some challenges associated with this, such as slipping back into using language that is not respectful and the need to regularly reassess what language is appropriate to use.

I’m still reminding myself of my language, but that’s what I think is the true success of the Framework, that I’m actually constantly aware of the words I use. If I have said something, I do reflect on that and try not to use that term again, or even if it’s not necessarily outlined that that term is incorrect in the Framework, I might look at what I’ve said and think that could have had an impact, maybe I should frame that another way. (Staff member)

3.7 Core Principle: Self Care

The literature review revealed very little reference to the importance of self-care for people sharing their story of lived experience. Self-care was not referred to in the key ingredients of education programs and only one research study was found that discussed its importance. In Jones et al. [23] study of the experiences of ‘experts by experience’ in Finland, the importance of setting personal boundaries was evident for presenters, as was the value of receiving training in this area. Setting personal boundaries included a focus on privacy and not revealing too much about themselves or their family. Equally important was the need to have boundaries around how often a person presents their story, as it is tiring and can be emotionally draining. While presenters commented on it being flattering to be asked to present their stories publicity, there were tensions associated with this, particularly if asked questions beyond what they were willing to share.

In the interviews, all but one of the experienced volunteers discussed the principle of self-care, with the majority emphasising the importance of looking after themselves, particularly in relation to their actual presentations. Volunteers had a range of strategies in place prior to, during, and after their presentation. Likewise, all new volunteers expressed the importance of this principle and felt that they would be incorporating practices into their routine to ensure they care for themselves when giving presentations. Self-care for volunteers was an important part of keeping themselves safe and related to aspects of privacy and the need to restrict the number of presentations to avoid becoming overwhelmed or exhausted.

Prior to giving a presentation, most experienced volunteers have in place strategies to ensure they are well prepared for the presentation.

I try and work out before I go what’s going to happen, because I need to prepare just for my own anxiety, and I try to predict the questions as well, because I don’t think well on my feet. (Experienced VE)

Always I want to prepare myself, to I remember breathing, self-care. Meditation in the car before I go in. (Experienced VE)

Staff and experienced volunteers also emphasised the importance of choosing to *not* present their story if they are not feeling up to it, with volunteers knowing they can withdraw even up to 30 minutes prior to the commencement of the presentation. Volunteers appreciated knowing that MIEACT cared for them and encouraged them to look after themselves through a strong focus on self-care.

If I’m having a really bad week, I might think “Maybe I shouldn’t do this presentation at the end of the week, maybe I should cancel it”. (Experienced VE)

Some educators shared how they incorporate self-care into the way they present their story.

There are actually some bits that are written, which are highlighted in yellow, and I have never, ever told them in front of an audience … I haven't ever deleted them … they're still in my story because for me they're a very important part of my story, but it very rarely feels safe for me to tell them as part of my story. (Experienced VE)

Several experienced VEs and one new VE discussed some strategies they have in place after presenting a session, with the most common being to not have anything scheduled immediately after the presentation.

I usually make sure I don't have anything on straight after a session, so I'll usually make sure there's a break of a couple of hours in my day afterwards. (Experienced VE)

Afterwards, I had a good chat, a debrief with one of the other facilitators, … and then I went to the gym, I could pay myself with time free to go and do something. (New VE)

New volunteers were also very positive about implementing self-care when they present their story to audiences. Several new volunteers discussed how they had already planned what some of these strategies would be, with some also acknowledging that they had learnt from what other presenters do.

It's quite important to emphasise self-care because … you may be vulnerable, so you can carry some self-care exercises, it will help you to recover and to be stronger. (New VE)

A lot of presenters have self-care items before their presentation, so when they go to present, if they're feeling bad they have a tool kit of things that can help them not re-traumatise themselves through their story. (New VE)

Although Self Care was acknowledged by most volunteers and staff to be vital, in the words of one long-term volunteer, '*I do always find self-care a bit difficult*'.

4 Discussion

This validation review considered the two main questions: to what extent the DoNOHarm Framework is supported by the current literature and how it is implemented and experienced by the volunteer educators.

4.1 Literature Review

A review of the published literature over the past 10 years (2011–2020) showed that there is strong evidence supporting mental health education sessions presented by people with lived experience. These programs have been implemented in secondary and tertiary education settings, incorporated into undergraduate and graduate medical and allied health tertiary education programs, and delivered in a range of workplaces. Positive outcomes of contact-based education programs include reductions in stigma, increased help-seeking intentions, and more understanding of and empathy for people with a mental illness [8].

The evidence base for three of the six DoNOHarm principles is also strong. There is substantial evidence for the importance of Context and Purpose, and the need for aligning the message to the context and having a clear purpose. There is also a strong foundation for education sessions having a Recovery Emphasis, with the impact of the stories of people with lived experience reported to be effective in reducing stigma, promoting help-seeking intentions, and increasing empathy for people with a mental health problem.

There is supportive evidence for Safe Talking and the use of safe language in recovery narratives, with several studies confirming the importance of this, although this was not identified as a key ingredient of the few contact-based education frameworks found in the literature. Safe language was important to avoid triggering distress for the presenter or the audience, to ensure there was not sufficient detail to allow for copying behaviours, and to avoid secondary trauma.

Although the intent of the Respectful and Inclusive Language principle is widely promoted in the mental health field, no recent studies focused on the benefits of this approach over other language styles. A person-first and recovery-focused approach was identified as a key ingredient for effective mental health education programs, and it is assumed that this includes language that is respectful and inclusive of people with a mental health problem. However, no recent research literature specifically examined the impact of language in this context.

There was no recent research into two of the DoNOHarm Framework principles—Limits to Helping and Self Care; these have not been the focus of research studies. They were also not included in the key ingredients of mental health education programs. Nevertheless, these two principles are supported by the many years of practical experience of MIEACT educators.

4.2 Experience of Volunteer Educators

The interviews with MIEACT volunteer educators and staff showed very strong endorsement of the Framework and that it is an effective guide to educators as they write their story and as they present it. This view was evident for educators with all levels of experience, from those who are very experienced to new volunteers who have not yet made a presentation, as well as the staff who support the volunteer educators. The Framework guides their use of language and the level of detail they include in their story, to keep both themselves and their audience safe. The Framework also ensures that presentations are relevant to each specific audience, giving educators flexibility to adapt their story according to the type of audience they are presenting to. Educators are also trained to read the audience as they give a presentation so that they can adapt their story if they notice that there are people in the audience who are looking distressed or uncomfortable.

As VEs and staff discussed the Framework, fives themes were evident in their responses, with safety being the theme that emerged in many aspects relating to the Framework. The relevance of the story and presentation was also a predominant theme with respondents emphasising that this was important to ensure they conveyed their message to their audience. The themes of confidence, hope, and engagement were also evident as participants discussed their understanding of the Framework, how they apply it, and how it could be improved.

Educators and staff were not aware of any other approaches that had been developed to guide people as they prepare and present their story of lived experience that would be as effective as the DoNOHarm Framework. Respondents emphasised that the Framework provides storytellers with a purpose-built guide to telling their stories safely, which is reassuring for presenters.

4.3 Limitations and Future Directions

The results of this study must be interpreted in light of its limitations. Firstly, the review was not a systematic review. Although this was originally intended, the literature was found to be too diverse and complex for such an approach. It was also conveyed by MIEACT that this was not the most useful approach for the organisation, as they were interested in what evidence there was to support the Framework, rather than uncovering all literature related to the multiple constructs that underpin it. Nevertheless, a rigorous review approach was undertaken to ensure that any relevant evidence was uncovered. However, in future research, a systematic approach to each of the key principles would provide a comprehensive and compelling resource.

Interviews were conducted with 60 percent of the volunteer educators and two-thirds of the small number of staff who support them. While all presenters and staff were offered the opportunity to participate, the interview times available were not convenient for some. There was no indication that this introduced any bias to the interview results. Care was taken to ensure confidentiality of responses, so that

any criticism of the Framework was anonymous. Despite this, there was almost no criticism, and the only improvements suggested were to make the evidence supporting the Framework more widely known.

It would be of considerable interest to know how audience members perceived the implementation of the Framework. Future research should consider the impact on different types of audiences targeted by such programs, particularly school students and community service staff like police. The Framework aims to ensure that the audience is not 'triggered' or overly upset by information in the presentations, but still sufficiently emotionally engaged to have their attitudes and behavior affected. To ensure that this is the case, the impact on a range of audiences would need to be investigated.

There is surprisingly little research into the impact of 'triggers' in non-clinical settings and this should be further investigated, particularly for school students. However, a recent review supports evidence of trauma-based triggers of distress for people with diagnosed mental health disorders [27]. People with PTSD are particularly vulnerable to intrusive thoughts where they reexperience trauma-based memories and images, causing them considerable distress. Distressing involuntary thoughts are also part of many other mental health problems, including agoraphobia, bipolar disorder, depression, eating disorders, generalized anxiety, health anxiety, obsessive-compulsive disorder, panic disorder, schizophrenia, and social phobia. Consequently, the potentially harmful impact of presenting for volunteers with lived experience of mental illness is clearly evident, and there is likely to be such potential for audience members with both diagnosed and unrecognised mental health conditions.

4.4 Conclusions

This validation review shows that MIEACT's DoNOHarm Framework is important for mental health education and that it has a sound evidence base from the published literature over the past 10 years, where there is published evidence. Where evidence is not available, the principles are based on widely accepted broader understandings and advocacy. Interviews with volunteer educators and the staff who support them confirmed that they understood the Framework and were easily able to apply it; they had few suggestions for improvement. Educators strongly supported the value and utility of the Framework. It was seen to be effective to protect the safety of both presenter and audience, ensure the relevance of the presentation, give educators confidence in their message and delivery, convey a hopeful message, and make certain that presentations were engaging for the audience. Frameworks, such as DoNOHarm, are fundamental for contact-based approaches promoting the value of people in the community having social contact with people with lived experience to reduce stigma, promote help-seeking, and educate people on mental illness and wellbeing.

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References

1. Kelly, C. M., Jorm, A. F., Wright, A. (2007). Improving mental health literacy as a strategy to facilitate early intervention for mental disorders. *Medical Journal of Australia, 187,* S26–S30.
2. Stuart, H., Chen, S. P., Christie, R., Dobson, K., Kirsh, B. et al. (2014). Opening minds in Canada: Targeting change. *Canadian Journal of Psychiatry, 59,* S13–S18. DOI 10.1177/070674371405901s05.
3. Chisholm, K., Patterson, P., Torgerson, C., Turner, E., Jenkinson, D. (2016). Impact of contact on adolescents' mental health literacy and stigma: The SchoolSpace cluster randomised controlled trial. *BMJ Open, 6,* e009435. DOI 10.1136/bmjopen-2015-009435.

4. Corrigan, P. W., Morris, S. B., Michaels, P. J., Rafacz, J. D., Rüsch, N. (2012). Challenging the public stigma of mental illness: A meta-analysis of outcome studies. *Psychiatric Services, 63,* 963–973. DOI 10.1176/appi.ps.201100529.
5. Happell, B., Wynaden, D., Tohotoa, J., Platania-Phung, C., Byrne, L. et al. (2015). Mental health lived experience academics in tertiary education: The views of nurse academics. *Nurse Education Today, 35,* 113–117. DOI 10.1016/j.nedt.2014.07.006.
6. Moll, S. E., Patten, S., Stuart, H., MacDermid, J. C., Kirsh, B. (2018). Beyond silence: A randomized, parallel-group trial exploring the impact of workplace mental health literacy training with healthcare employees. *Canadian Journal of Psychiatry, 63,* 826–833. DOI 10.1177/0706743718766051.
7. Happell, B., Bennetts, W. (2016). Triumph and adversity: Exploring the complexities of consumer storytelling in mental health nursing education. *International Journal of Mental Health Nursing, 25,* 546–553. DOI 10.1111/inm.12244.
8. Rickwood, D. J., Cavanagh, S., Curtis, L., Sakrouge, R. (2004). Educating young people about mental health and mental illness: Evaluating a school-based programme. *International Journal of Mental Health Promotion, 6,* 4–13.
9. Bocking, J., Happell, B., Scholz, B., Horgan, A., Goodwin, J. et al. (2019). 'It is meant to be heart rather than head'; International perspectives of teaching from lived experience in mental health nursing programs. *International Journal of Mental Health Nursing, 28,* 1288–1295. DOI 10.1111/inm.
10. Read, S. A., Rickwood, D. J. (2009). Volunteering as a community mental health educator: Positives and negatives for recovery. *Advances in Mental Health, 8,* 194–203. DOI 10.5172/jamh.8.2.194.
11. Weare, K., Nind, M. (2011). Mental health promotion and problem prevention in schools: What does the evidence say? *Health Promotion International, 26,* i29–i69. DOI 10.1093/heapro/dar075.
12. Mental Illness Education ACT (MIEACT) (2020). *Do no harm Framework. A guide to sharing and hearing stories safely.* Canberra: MIEACT.
13. Wilson, C. (2014). Semi-structured interview. *Interview techniques for UX practitioners: A user-centered design method*, pp. 23–42. Elsevier.
14. Qu, S. Q., Dumay, J. (2011). The qualitative research interview. *Qualitative Research in Accounting and Management, 8,* 238–264. DOI 10.1108/11766091111162070.
15. Braun, V., Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3,* 77–101. DOI 10.1191/1478088706qp063oa.
16. Srivasta, P. (2009). A practical iterative framework for qualitative analysis. *International Journal of Qualitative Methods, 8,* 76–84. DOI 10.1177/160940690900800107.
17. Corrigan, P. W., Vega, E., Larson, J., Michaels, P. J., McClintock, G. (2013). The California schedule of key ingredients for contact-based antistigma programs. *Psychiatric Rehabilitation Journal, 36,* 173–179. DOI 10.1037/prj0000006.
18. Corrigan, P. W., Michaels, P. J., Vega, E., Gause, M., Larson, J. (2014). Key ingredients to contact-based stigma change: A cross-validation. *Psychiatric Rehabilitation Journal, 37,* 62–64. DOI 10.1037/prj0000038.
19. Knaak, S., Modgill, G., Patten, S. B. (2014). Key ingredients of anti-stigma programs for health care providers: A data synthesis of evaluative studies. *Canadian Journal of Psychiatry, 59,* S19–S26. DOI 10.1177/070674371405901s06.
20. Llewellyn-Beardsley, J., Rennick-Egglestone, S., Callard, F., Crawford, P., Farkas, M. et al. (2019). Characteristics of mental health recovery narratives: Systematic review and narrative synthesis. *PLoS One, 14,* e0214678. DOI 10.1371/journal.pone.0214678.
21. Maunder, R. D., White, F. A. (2019). Intergroup contact and mental health stigma: A comparative effectiveness meta-analysis. *Clinical Psychology Review, 72,* 101749. DOI 10.1016/j.cpr.2019.101749.
22. Fitzgerald, K., Paravati, E., Green, M. C., Moore, M. M., Qian, J. L. (2020). Restorative narratives for health promotion. *Health Communication, 35,* 356–363. DOI 10.1080/10410236.2018.1563032.
23. Jones, M., Pietilä, I. (2020). Personal perspectives on patient and public involvement—Stories about becoming and being an expert by experience. *Sociology of Health and Illness, 42,* 809–824. DOI 10.1111/1467-9566.13064.

24. Ng, F., Charles, A., Pollock, K., Rennick-Egglestone, S., Cuijpers, P. et al. (2019). The mechanisms and processes of connection: Developing a causal chain model capturing impacts of receiving recorded mental health recovery narratives. *BMC Psychiatry, 19,* 413. DOI 10.1186/s12888-019-2405-z.
25. Martinelli, T. F., Meerkerk, G. J., Nagelhout, G. E., Brouwers, E. P. M., van Weeghel, J. (2020). Language and stigmatization of individuals with mental health problems or substance addiction in the Netherlands: An experimental vignette study. *Health & Social Care in the Community, 28,* 1504–1513. DOI 10.1111/hsc.12973.
26. Jensen, M. E., Pease, E. A., Lambert, K., Hickman, D. R., Robinson, O. et al. (2013). Championing person-first language: A call to psychiatric mental health nurses. *Journal of the American Psychiatric Nurses Association, 19,* 146–151. DOI 10.1177/1078390313489729.
27. Boysen, G. A. (2017). Evidence-based answers to questions about trigger warnings for clinically-based distress: A review for teachers. *Scholarship of Teaching and Learning in Psychology, 3,* 163–177. DOI 10.1037/stl0000084.

Appendix 1

Lived experience story sharing guides:

- *Story sharing guidance developed by Scottish Recovery Network* https://www.scottishrecovery.net/wp-content/uploads/2020/12/A-_Guide_to_Sharing_Recovery_Stories.pdf
- *Share your story. A how-to-guide for digital storytelling developed by the Substance Abuse and Mental Health Services Administration (SAMHSA)* https://www.samhsa.gov/sites/default/files/programs_campaigns/brss_tacs/samhsa-storytelling-guide.pdf
- *Telling your recovery story: Giving meaning and purpose to your pain by using it to help someone developed by Advocates for Human Potential* https://mentalhealthrecovery.com/info-center/telling-your-recovery-story/

Recovery-oriented language guides:

- *Recovery Oriented Language Guide by Mental Health Coordinating Council (Sydney)* https://mhcc.org.au/wp-content/uploads/2019/08/Recovery-Oriented-Language-Guide_2019ed_v1_20190809-Web.pdf
- *Recovery Oriented Language Guide by the New York Association of Psychiatric Rehabilitation Services* https://static1.squarespace.com/static/58739f64e6f2e14a3527a002/t/5bb4f39124a6940b1fd2f909/1538585490002/Recovery+Oriented+Language+Glossary+2017.pdf.