IMPROVING SERVICE USER INVOLVEMENT IN MENTAL HEALTH NURSING EDUCATION: SUGGESTIONS FROM THOSE WITH LIVED EXPERIENCE

ABSTRACT

Service user involvement in mental health nursing education is increasing and a developing evidence base is demonstrating more positive attitudes towards people labelled with a mental illness. To date, most research on this approach has focused on the perspectives of nursing students, with very limited research drawing on the expertise and opinions of service users. The aim of this study was to explore potential improvements in mental health nursing education, and ways service user involvement can be enhanced as defined by service users themselves. An international qualitative research project was undertaken involving focus groups with service users (n=50) from Australia and five European countries. The research was coproduced between Experts by Experience (service users) and mental health nurse academics. Data were analysed thematically. Findings reflected two broad themes: 1) improvements to content, including: further emphasis on developing emotional intelligence, understanding mental distress and broader context of care; 2) Improvements to service user involvement, including: support, format, and teaching and learning techniques. These findings provide direction for maximising the benefits of service user involvement and show the value of the expertise of service users.

KEYWORDS

COMMUNE (Co-production in mental health nursing education)

Coproduction

Education of health professionals

Experts by Experience

Mental health

Nurse education

Service Users

INTRODUCTION

The positive contribution service users make to the education of health professionals is being increasingly acknowledged (Arblaster, Mackenzie, & Willis, 2015; Horgan et al., 2018). Service users enhance the quality of the educational process and reduce negative attitudes towards people labelled with mental illness in students (Happell, Platania-Phung, et al., 2019; Modgill, Patten, Knaak, Kassam, & Szeto, 2014; Simmons, Jones, & Bradley, 2017).

The evidence base in support of service user involvement in educating health professionals is growing. Research suggests that the inclusion of service users is highly regarded by key stakeholders, and considered extremely valuable by nursing students and students of other health professions (Arblaster et al., 2015; Byrne, Platania-Phung, Happell, Harris, & Bradshaw, 2014; Goossen & Austin, 2017; Gordon, Ellis, Gallagher, & Purdie, 2014; Happell et al., 2014; Happell, Platania-Phung, et al., 2015; Happell, Platania-Phung, et al., 2019; Horgan et al., 2018; Mahboub & Milbourn, 2015; O' Donnell & Gormley, 2013; Ridley, Martin, & Mahboub, 2017; Scammell, Heaslip, & Crowley, 2016; Schneebeli, O'Brien, Lampshire, & Hamer, 2010). Mental health nurse academics have reported the positive contribution made by service users to mental health nursing education (Dorozenko, Ridley, Martin, & Mahboub, 2016; Happell, Wynaden, et al., 2015); although concerns regarding the authenticity, reliability and necessity of this involvement have

been expressed (Happell, Bennetts, Platania Phung, & Tohotoa, 2015; Happell, Bocking, Scholz, & Platania-Phung, 2019).

A major limitation of the current literature on this topic is its omission of service user perspectives. The current literature base focuses primarily on the perspective of students, and albeit less frequently, the perspectives of clinical/nurse academics (Happell et al., 2014). For example, a systematic review published in 2014, identified 28 studies addressing service user involvement in pre-registration education. None examined the topic from the perspective of service users (Happell et al., 2014).

Students have made recommendations to improve the service user involvement in their nursing programmes. These fall into suggested amendments to structure; more time with service users; being taught by service users earlier in the programme; focusing on assessment; improved consistency; changes to content; and inclusion of multiple service user perspectives, with a balance of positive and negative experiences shared in the narratives (Happell, Waks, Horgan, et al., 2019). Students are major stakeholders in their education and their views and opinions are important. Yet student perspectives are distinct to and thus cannot be interchanged with the views of service users.

The literature suggests service user involvement has developed through their teaching on existing programs as guest lectures, often involving them

telling their 'story' or narrative of illness/wellness (Happell, Platania-Phung, et al., 2015; Horgan et al., 2020; McCann, Moxham, Usher, Crookes, & Farrell, 2009). Students reported that these stories were useful in understanding more about the entire experience of being labelled with mental illness and seeing people who use mental health services as far more than their diagnosis (Happell, Waks, Bocking, Horgan, Greaney, et al., 2019; Happell, Waks, Bocking, Horgan, Manning, et al., 2019). However, this approach does not acknowledge the experiential knowledge that service users have gained by virtue of their own lived experience (Byrne, Stratford, & Davidson, 2018; Scholz, Bocking, & Happell, 2018).

There is limited opportunity for service users to input into curricula design, and thereby influence the education of health professionals. By default, control over curriculum content and delivery remains in the hands of the health professionals and their regulatory bodies and logically reflects the predetermined views of how health professionals within the discipline should be educated for future practice. There is some evidence of service user involvement in other aspects such as curriculum design and assessment of student learning (Happell, Wynaden, et al., 2015), yet most service uses are employed on a casual basis. Therefore, their capacity to make substantial contribution to curriculum reform is limited. A study was undertaken in Australia to examine consumers' priorities for curricula for health professional education, and preferred modes to participate (Arblaster et al., 2018).

Findings suggested service users desired active involvement in curricula including design, delivery and review.

A limitation of the existing research is that it has primarily focused on evaluating current practices with little attention given to what could be improved. Furthermore, most research has been conducted in single sites and as such has tended to evaluate or explore the practices of one or a small number of service user educators/academics. COMMUNE (Co-produced Mental Health Nursing Education) differs in that it is an international research project conducted in five countries in Europe and one site in Australia. COMMUNE was implemented to evaluate service user (referred to in the study as Experts by Experience [EBE]) involvement in mental health nursing education. This approach enabled service user involvement in mental health nursing education to be explored across a broader geographical footprint than has previously occurred. A primary objective of the study was to coproduce a learning module to be delivered to mental health nursing students by EBE. The expertise of people labelled with a mental illness and with experience of mental health service use was paramount to this project in all stages. The first stage in informing the development of the learning module was to conduct focus groups with people with lived experience of mental distress and mental health service use. The aim was to gain service users' perspectives on how service user involvement in mental health nursing education could be enhanced.

AIM

The aim of the COMMUNE study was to develop a learning module based on service users' perspectives, experiences and opinions about service user involvement in mental health nursing education. The purpose of this paper is to report on service users' views regarding potential improvements to their involvement in mental health nursing education.

METHODS

Design

The research was undertaken using a qualitative exploratory approach (Stebbins, 2001). A flexible method was used in light of the paucity of previous research which addresses this topic from the specific perspective of service users. Qualitative, exploratory methods ensure participants can contribute their perspectives, which might otherwise be hindered or constricted by the theoretical perspective or philosophical approach adopted by the research team (Sandelowski, 2000).

The study design of the COMMUNE project aspired to achieve co-production with EBE and mental health nurse academics as collaborative partners. Co-production involves equitable collaboration on each stage of the project, including conception, design, ethical approval, data collection

and analysis. Flexibility of methods is pivotal for co-produced research. The approach and commitment to co-production principles enabled the perspectives of EBE to be embedded in the research, rather than risk their contribution being diluted, or worse, confined to tokenism (Gillard, Simons, Turner, Lucock, & Edwards, 2012; Roper, Grey, & Cadogan, 2018).

Setting

The research was undertaken at six sites in Europe (Iceland, Ireland (two locations Cork and Dublin), Finland, the Netherlands and Norway), and one site in Australia. One nurse academic and one EBE member of the research team from each university hosted at least one focus group at each site.

Recruitment

People, 18 years of age or older, with previous experience of utilising mental health services were invited to participate in the study. Local mental health service user groups facilitated recruitment by contacting their own membership via email and newsletters and by posting advertisements in prominent locations. In total, 8 focus groups were held, one at each location and *two in Norway*. Focus groups were held at a centrally located community centre, university, or community centre. Fifty service users in total participated in the focus groups. For further information about the participants, see Table One.

Insert Table One here

Data Collection

The focus groups were of 60 – 180 minutes duration to facilitate open communication and detailed discussion. The groups were moderated by an EBE and nurse academic, reflecting the principles of co-production and respecting the unique perspectives each expertise brings to data collection. Participants were presented with a broad question about how service user involvement in nursing education could be improved or enhanced. The interview guide was semi-structured and intended to enhance conversation rather than restrict it to a particular focus and participants were encouraged to share their experiences and perspectives beyond the specific questions asked. For analysis, focus groups were audio recorded and transcribed verbatim. This process enabled the research team to receive a full and discursive account of the qualitative data.

Ethics

The research was approved by the Ethics Committee at each university. A comprehensive overview of the research was provided to those who expressed interest in participating, verbally and in writing. Prior to agreeing to participate, participants were informed about the voluntary nature of participation and their right to withdraw from the study at any time without

explanation or penalty. The confidentiality arrangements were reiterated and participants were reminded that none of their identifying information would be published. Participants were encouraged to ask questions and seek more information before agreeing to participate and sign the consent form. Interview transcripts and audio-recordings are being securely stored in each country according to the specific local ethics committee requirements.

Data analysis

Data analysis was conducted in two phases. At each research site, it was undertaken independently by an EBE and nurse academic. Analysis was directed by the framework developed by Braun and Clarke (2006). A detailed overview of the analysis is presented in Table Two. After completing analysis, researchers convened to compare and review their respective findings. Discussion and negotiation was undertaken until consensus was achieved. The research team was confident this process ensured service user perspectives were accurately presented throughout the research findings (Gillard et al., 2012).

The second phase involved collating data from each site, following the same process as for Phase One. The final analysis was presented to a meeting of the full research team (12 EBE and 10 nurse academics) to review the analysed data in total. The findings were endorsed, subject to some modifications to language and terminology.

Insert Table Two about here

FINDINGS

Improvements to nursing education was a main theme identified from this research. This included two subthemes:

1. Improvements to content
2. Improvements to service user involvement

Improvements to content

Participants suggested the curricula needs to place further emphasis on student's personal development and fostering their emotional intelligence to enhance their interpersonal skillset:

> …if they [students] see an individual has broken down in tears, to be equipped emotionally with that emotional intelligence to deal with that aspect of somebody breaking down in front of them. (Australia)

> Some personal development and so on. And that's it. So if you are to see that, really you can't put, teach or look after without learning yourself if you're teaching somebody something or looking after yourself

> if you're trying to look after someone. It's just the way the world is. I mean that's just the way basic human life thinks. (Dublin)

Participants found nurses with well-developed interpersonal skills can make a strong impact in assisting them to manage their distress, particularly in the inpatient environment, for example:

> …the experiences I have had when mental health nurses were more engaged, more interested, show better communication, assisted with other things … like if you had problems. (Australia).

Participants suggested nurses need an increased understanding of mental distress, including triggers, counselling approaches, prevalence, and diagnostic frameworks (including limitations of this model):

> some base in psychology and the things that effect your mental health like the things that they don't do, family systems, all the different things that trigger people … they could do a bit of counselling … like a bit of therapy … to like make their careers different (Cork)

> Basically, teach them about mental health, ... the idea that … mental or emotional distress is or psychosocial distress is a part of life and to sort of normalize it and say that it can happen to anyone that it's not … an

> indicator of personal weakness or disease but that it's something that anyone can experience given any kind of circumstances. You know life circumstances (Dublin).

> One of the good ways to try and guide nurses towards mental health is also to give them those figures that its one in four; or its one in four teenagers, it is one in five adults. So, if they know four people chances are they are going to know someone at some stage of their life will be affected by mental health (AUS)

Finally, it was recommended that students receive practical content to aid their understanding of the needs of the service user in the broader context, and to assist their understanding of the contemporary socio-political context of mental distress:

> Everyday skills like money management, nutrition … I mean basic health skills, it's not just the mind they're dealing with. They're dealing with the whole body …. it's social, it's political, it's all different problems (Cork).

> …to learn more about the whole person, rather than the ill person they see in hospital or here in other services. (Australia).

Improvements to service user involvement

Support

Participants reported, providing equitable support for service users was considered essential in creating a safe and comfortable teaching environment. For some participants, having more than one service user educator was a potential solution to this problem:

> I think it is important to have some time after a session where we can talk about it and support each other. (Iceland)

> I think you should maybe have a number employed [EBE] so you've got, not just one scope of mental illness, one diagnosis covered, you've got a bit of scope. (Australia).

> if you're one service user in a room full of nurses or people in academics or make sure that that person hasn't or isn't alone in that (Dublin)

Others emphasised the importance of supporting students and nursing academics who might not automatically feel comfortable working with service users as educators:

> I know in some health services they [health professionals] feel a bit threatened when service users and experts by experience come too close (Norway).

Format

One of the major changes participants identified to format was to increase the amount and the spread of students' exposure to service user educators to achieve greater benefits from the experience:

> I would have liked to have more hours to teach in total, spread across the years. We are there for two hours, but we would have liked to come back after a while so people would have had time to think, and gotten even deeper into what we are presenting (Norway).

> Give the opportunity to experience to contribute to something beautiful, something new. …. The experience to do a whole lesson by yourself will grow by itself (Netherlands).

It was identified that this process would provide the opportunity for students to reflect on and ultimately build on their early encounters with service user educators and other experiences gained through aspects of their education such as clinical experience:

> Just don't make it the once, like we do Year 1… and that's it. But really, we should be brought in at the end as well, because they'll have more questions, more insight … and then you can really give them the lived experience… almost like a peer support role, where the nurses can come back to that person with experiences… to help them digest what they have seen (on placement). They have done some experience, they're starting to build up those questions that are really best answered by people with a lived experience. [AUS]

Teaching and learning techniques

Participants described story telling as an important teaching technique. Story telling was described as providing their own first hand experiences to assist students to understand the experiences service users face and how it impacts them at the personal level:

> Maybe we should give the students a more practical understanding of what people are struggling with when it comes to mental health problems (Norway).

The need to share both the positive and negative aspects of their experiences was emphasised by some participants:

> The good experiences should be heightened and the bad experiences should be heightened… I'd be highlighting the bad experiences to see how it can change [Cork]

Story telling was also seen as an important way to demonstrate the journey of recovery:

> The story of recovery and the discussion of the processes to get there is essential (Australia).

Story telling was also considered a good start, allowing students to reflect on their own life story:

> My experience is that it become dead quiet when I tell my story in class. And that then personal questions and personal stories follow from those who listened. So you can clear the road for others to share their story (Netherlands).

One participant suggested panels and similar collective fora could be a means to create interactive communication as an alternative to traditional storytelling, and provide a more active and engaging environment for students enabling specific issues of interest to them to be addressed:

> I think those sorts of panels and forums could be good way, also, of getting a bit of interaction between nurses and students and the consumers, and as I say, those who work with consumers as families and carers that have those sorts of positive relationships… Have question and answer forums with them so it is not a passive experience of listening to a story… I'm sure the student nurses will have tons of questions (Australia).

Role play and case studies were regarded as a particularly effective tool in encouraging students to better understand the experience of being labelled with a mental illness:

> I can imagine that we could have role play… because it is very effective to see how that works (Iceland).

Role plays can be used in specific situations to encourage students to truly empathise with these circumstances:

> I think role play is a fantastic way to feel what it's like to be in a helpless role asking for help. I think it's then much easier to get across the user's perspective (Norway).

Participants presented specific examples of role plays they had found to be effective learning tools:

> You have someone having a conversation and then you have two people over their shoulder saying things at them. Sometimes one person will say nice things and the other person will say horrible things, and it's trying to hold a conversation whilst you have all of these voices going on. People do that for a minute and sit there and think, oh my God, I could not possibly live like that, and then you tell them, well, that's how some people live. That's their experience (Australia).

> The best experience I ever got was we had to mime or role play a person going in (hospital) for the first time and I tell you it was powerful [Dublin]

In relation to case studies, one participant highlighted:

> You actually need to pre-empt these sorts of training interactions with something that gets them thinking along that pathway. And case studies can be both confronting but also quite enlightening (Australia).

DISCUSSION

The findings from this research provide a better understanding of service users' views about mental health nursing education, both in terms of improving the content, and in enhancing the involvement of service users teaching nursing students from their perspective. Two main areas were

identified where service users believed more content was required; stronger focus on personal development, communication and interpersonal skills; and understanding the socio-political context of distress.

Participants described nurses with well-developed emotional intelligence and interpersonal skills as crucial to their improvement and well-being. The importance of communication skills has been previously identified in the literature (Delaney, Shattell, & Johnson, 2017; Gunasekara, Pentland, Rodgers, & Patterson, 2014; Molin, Graneheim, & Lindgren, 2016; Molin, Graneheim, Ringnér, & Lindgren, 2019; Molin, Lindgren, Graneheim, & Ringnér, 2017). Interpersonal skills are considered the cornerstone of nursing practice and essential for holistic and recovery focused practice (Byrne, Happell, Welch, & Moxham, 2013a; Goodrich, 2016; Jasemi, Valizadeh, Zamanzadeh, & Keogh, 2017; Kennedy, 2017; Santangelo, Procter, & Fassett, 2018; Tatsumi, 2017). While participants valued these skills they considered nurses to be frequently unavailable to spend time with them. Criticisms of interpersonal interactions with nurses have been noted in the literature (Cutcliffe & Happell, 2009; Ejneborn Looi, Engström, & Sävenstedt, 2015; Stewart et al., 2015).

The findings highlight that if nursing is truly to provide holistic and recovery-focused practice, the perspectives of service users are crucial. Communication and interpersonal skills within curricula and developed in conjunction with a focus on emotional intelligence and personal

development must be scrutinised and improved to ensure nurses are well prepared to provide person-centred care within mental health services.

Participant responses indicated a desire for nurses to have a greater understanding of the broader context of mental distress, that might facilitate the service user adjusting and receiving necessary supports after discharge. The tendency for health service delivery to focus on medical care and treatment is acknowledged in the literature (Gottlieb, Wing, & Adler, 2017; Mossabir, Morris, Kennedy, Blickem, & Rogers, 2015). Increased awareness of community networks have been found to be valuable to people accessing mental health services and contribute to improved outcomes (Webber & Fendt-Newlin, 2017). However, despite this, referrals are not commonly made (Gottlieb et al., 2017). Nurses are well positioned to link service users with community resources and yet remain an underutilised resource (Delaney et al., 2018). Therefore, it is imperative that undergraduate mental health nursing education extend its focus beyond the inpatient unit and into the community.

Improvements that service user participants considered necessary for effective involvement in mental health nursing education included the availability of support for the service users undertaking these roles. This has been previously identified as important to service users involved in the education of health professionals (Happell, Bennetts, et al., 2015; Horgan et al., 2020; Meehan & Glover, 2007). In response to the identified lack of

support provided to service users in education roles, standards have recently been developed to support service user roles (Horgan et al., 2020). The provision of support includes external supervision, where possible provided by an EBE, supportive teamwork and debriefing.

Participants in the current study suggested having more than one service user involved in the teaching, primarily so they could provide support for one another. Individual roles have been acknowledged as depriving service user educators of the collegiality generally enjoyed by health professionals in the academic environment (Happell & Roper, 2006b). The value of more than one consumer providing education has been raised elsewhere in the literature from the perspective of nursing students (Happell et al., 2014; Happell, Waks, Horgan, et al., 2019) and mental health nurse academics (Happell, Bennetts, et al., 2015; Happell, Bocking, et al., 2019). In these instances however, the underlying rationale pertained to the issue of 'representativeness' with one service user being considered insufficient to represent a range of experiences. The expectation that individual service users be representative has been articulated, disempowering service users as following their own agenda rather than presenting perspectives from a broader constituency, an expectation rarely placed on health professionals (Happell, 2010; Happell & Roper, 2006a; Scholz, Stewart, Bocking, & Happell, 2017). This is an interesting example of the same strategy being considered from very different perspectives, with very different intentions and outcomes, further reinforcing the importance of the service user voice. To avoid

establishing separate rules for EBE, the number of EBE in the classroom should be discussed with them on an individual basis.

Participants commented on the duration and timing of service user involvement in mental health nursing education. They believed longer periods of time, ideally spread over the years of study would maximise benefits of service user engagement by providing the opportunity to reflect and raise additional issues and questions. This issue was also raised by nursing students themselves (Happell, Waks, Horgan, et al., 2019), further supporting the value of increased exposure of service user education to nursing students.

Given the noted barriers in terms of funding shortages (Happell, Bennetts, et al., 2015) and attitudinal barriers posed by some nurse academics (Happell, Bocking, et al., 2019), there is work yet to be done. Nurse academics, particularly those in control of funding and resource allocation must value the unique expertise service users have developed through their own lived experience of mental distress and mental health service use (Byrne et al., 2018) and their contribution to nursing education and academia cannot be achieved by any other means (Byrne, Happell, Welch, & Moxham, 2013b; Happell et al., 2018; Russell, 2014).

Participants suggested specific learning techniques they felt should be utilised in mental health nursing education, including role plays and panel discussions. Telling their individual stories was seen as a particularly useful

technique in demonstrating their own recovery as well as the personal impact of their mental distress and mental health service use. Story telling is identified as a powerful tool in service user delivered education (Happell & Bennetts, 2016; Our Consumer Place, 2011). The use of story is controversial, particularly when it presented as the expected contribution service users make to education, as is frequently the case (Happell & Bennetts, 2016). The service user participants in this research have identified the value of story from their perspective and identify it as an important learning tool. Clearly their autonomy must be respected. It is important to recognise that story telling can have strong emotional impacts and service users should be well supported and debriefed appropriately (Happell & Bennetts, 2016; Our Consumer Place, 2011).

Limitations

As a qualitative research study there are inherent limitations, primarily relating to the lack of generalisability of the findings to broader populations. As an international study with 50 participants from six countries, the findings are potentially more robust than single site studies. Nevertheless, they are the perspectives and opinions of these service user participants themselves.

CONCLUSIONS

The increase in service user involvement is a positive and important development in the education of health professionals, with multiple benefits for student learning. Acknowledging and respecting the unique knowledge service users bring, based on their lived experience of mental distress, service use and recovery, is essential. This expertise is critical if we are to further develop and maximise the benefits derived from service users as active participants in mental health education. That the perspectives of service users have not been actively sought to contribute to developments is a serious omission, and one partially remedied by the present study.

The service user participants in this study have provided important insights into how their involvement in health education can be strengthened. While their views are in part similar to those of students and mental health academics, they have expressed differing priorities, revealing gaps and the need to strengthen supports provided to EBE in a teaching role. Both the responses from nurse practitioners/academics and the views of EBE serve to demonstrate the inherent value of the lived experience and EBE/service user voice in health education. As a coproduced, international study of service user perspectives, the authors hope these findings contribute to a deeper understanding of service users' roles in mental health education, within the classroom and in all stages of health professional education.

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			Female	Male	Total
Finland			1	6	7
Australia			6	3	9
Netherlands			2	3	5
Norway	**Male**	**Female**	2	6	8
1st group	1	3			
2nd group	1	3			
Ireland (Dublin)			4	4	8
Ireland (Cork)			4	2	6
Iceland			3	4	7
Total			22	28	50

Table One: Focus group participants

Stage one	To gain familiarity with the data and its essential meaning, transcripts are read multiple times independently by at least two researchers. Once this understanding of the data was reached, each researcher ascribed codes to the data according to common components of content. A draft of the preliminary codes was compiled.
Phase two	The coding framework was examined and reviewed by each researcher to ascertain specific meaning from data and identify, from the framework, patterns in content, representing major themes.
Phase three	Following completion of analysis, researchers in each country, met to review discuss the coding framework and the emerging themes identified. Differences of opinion were articulated and considered, with modifications occurring until consensus was achieved.
Phase four	Themes and subthemes were presented via a conceptual map, allowing further review of the thematic structure by all members of the research team. Further revision was undertaken until themes were clearly articulated and researchers considered them as an accurate depiction of the substance of the data from each country.

Phase five	Data analysed individually at each research site were combined for the purposes of reanalysis. This process was undertaken by three researchers from the lead university (one expert by experience, one nurse academic, and one student). Following completion, the full research team met face-to-face to review and discuss the draft findings. Key data, themes, and sub-themes from the collated data set was reviewed, edited and modified as necessary until the team members was satisfied the final document adequately reflected the perspectives and opinions of participants from their country. EBE were centrally involved in all stages of data analysis, ensuring principles of co-production were followed as closely as possible, and their perspectives were faithfully reflected in the final document. During the face to face meeting, several changes of names and wording of themes were made to more accurately reflect the language of service users and to enhance the authenticity of the findings and their relevance across an international audience.

Table two: Data analysis framework