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"It is meant to be heart rather than head"; Perspectives of teaching from lived experience in mental health nursing programs: The COMMUNE project

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International Expert by Experience perspectives of teaching in mental health nursing programs: The COMMUNE project

Abstract

Consumer participation is a clear expectation of contemporary mental health policy. Most activity has concentrated in direct service delivery, and academic roles for mental health consumers have been slow to establish. An international project was undertaken to implement and evaluate meaningful consumer involvement in mental health nursing education. A learning module was co-produced between 'Experts by Experience' (drawing on experience of mental distress and service use) and Mental Health Nurse Academics. This qualitative exploratory study aimed to capture how Experts by Experience perceive their contribution. Interviews were undertaken with Experts by Experience who delivered the learning module. Data were analysed thematically and subsequently interpreted with Critical Social Theory. Two main themes emerged from the findings: '*there wasn't a barrier'* described how personal narratives enhanced relationships between Experts by Experience and students; and, '*made the human being visible',* described their experiences of allowing students to see the person behind a diagnosis. These findings suggest Experts by Experience teaching is valuable and

potentially a tool in redressing stigma. Addressing poor public perceptions could attract higher numbers of quality practitioners to mental health and meet identified workforce shortages. The findings presented here strengthens the evidence-base for Expert by Experience roles in mental health professional education. These findings can be considered in international curricula reviews and aid progress towards a more socio-political, humanistic focus in mental health nursing, congruent with rights-based reform agendas.

KEYWORDS:

Consumer participation
Experts by Experience
Mental Health
Mental Health Nursing
Nursing Education
Stigma

Introduction

Consumer participation is enshrined in contemporary mental health policy, as both an ethical imperative and vital quality assurance mechanism (Commonwealth of Australia 2010; Commonwealth of Australia 2013; Commonwealth of Australia 2017; Health and Consumer Protection Directorate-General 2005; Health Service Executive 2018). This policy lever translates into an increasing number of positions for people with lived experience of 'mental illness': as support workers, facilitators, consultants and educators (Byrne *et al.* 2016; Bennetts *et al.* 2013). Terms to refer to those whose work draws on experiential rather than professional knowledge are contentious and varied.

Consumer involvement in academic mental health nursing education is a relatively recent development. Despite the limited yet growing body of

research indicating a positive impact on student learning (Happell *et al.* 2014a; O'Donnell & Gormley 2013), established academic roles are rare (Happell *et al.* 2015). Indeed, consumer participation in academia occurs in an ad hoc fashion (if at all), and to date, there has been little systemic input into nursing curricula design (Happell *et al.* 2015; McCann *et al.* 2009). The call for more comprehensive lived experience involvement in mental health nursing education is supported at the broader level (Mental Health Nurse Education Taskforce 2008).

There is a dearth of research exploring the features of this type of student learning, and none to date articulate the collective perspectives of those delivering the content. The literature focuses primarily on student perspectives and outcomes (Stacey & Pearson 2018; Happell *et al.* 2014b; Byrne *et al.* 2014; Byrne *et al.* 2013), and is restricted to one educational setting.
This paper describes finding from the COMMUNE (Co-production of Mental Health Nursing Education) project, a novel multi-site approach to the development, delivery and evaluation of consumer involvement in nursing education. A key goal was to coproduce all aspects of the project. This innovative research was conducted across seven universities in six countries (Iceland, the Netherlands, Norway, Ireland, Australia and Finland). The current study is the first to explore the impact of lived experience teaching in nursing education from the viewpoint of those delivering the educational content. The lived experience educators in this study unanimously agreed to use the term 'Expert by Experience' (EbE) to describe themselves. EbE conveys both the value of the expertise, and its phenomenological nature, as distinct from professional or academic knowledge. The term was considered by the research team to be preferable to others which imply passivity ('patient', 'consumer') or defined by one's current orientation to services ('service user'). Reclaimed terms such as 'Mad' did not translate well into some language groups (e.g. Icelandic: 'out of control') (Biering 2017).

The COMMUNE project aimed to embed lived experience perspectives into nursing education in a meaningful way. The project co-produced a module to be taught in undergraduate nursing programs between nursing academics and EbE educators. The module contained a number of themes that were initially derived from focus groups held in each country with people who had an experience of a mental illness diagnosis (n=50) (Horgan et al, 2018). The identified qualities which COMMUNE aimed to foster in students are listed in Table 1.

Insert Table 1 here.

The team at each research site developed relevant original teaching material to foster the qualities in students identified above. A key component was the sophisticated inclusion of lived experience perspectives combined with participatory classroom exercises. Narratives illustrated the concepts of study. There was a focus on the development of a responsive interpersonal skillset and understanding the constraining socio-political factors behind clinical presentations, such as stigma.

Theoretical Framework

Research indicates that incorporating EbE perspectives in the education of mental health professionals can promote empathic attitudes and redress student stigma of 'mental illness' (Corrigan *et al.* 2012; Byrne *et al.* 2014). As this attitudinal shift relates to personal values held about groups in society, it is useful to explore through discourse analytic techniques which focus on power and social patterns.

Critical Social Theory (CST), as conceptualised by German philosopher Jürgen Habermas (McCarthy 1978), was deemed most suitable for the present study. The flexible ontological position rejects scientific

absolutism/objectivism, and instead views truth as socially constructed and in need of critical evaluation. CST was introduced in nursing education in the early 1970s in response to criticism that a purely biomedical approach to nursing practice was too narrow (Browne 2000). A rational-technical pedagogical model was unable to account for adverse social conditions which impacted on health, such as poverty, racism and discrimination (Duchscher 2000). Habermas claimed that nursing education must have an emancipatory aspect (Wells 1995). Critical enquiry is one way to develop this element, where meaning is created through an egalitarian dialogue which exposes tensions and constraints to current assumptions (Duchscher 2000). The COMMUNE EbE teaching provided such a dialogue.

Aims and Objectives

The aim of the current study is to investigate the collective views of the Experts by Experience who taught the COMMUNE module, and their perceived contribution to nursing student learning.

Methods

Design

The novel qualitative research design used a combination of inductive and deductive analytic process in four distinct phases. First, individual interviews were conducted with EbEs at each site. Next, the nursing academic and EbE team from each site coproduced a thematic analysis as described by Braun & Clarke (2006). The resulting themes were then translated into English (if required) and sent to the Australian EbE. All the themes from each site were then pooled. The entire data corpus was analysed once more, according to Braun & Clarke's multiphasic process. These three phases adopted an inductive, exploratory approach. Such an approach is ideal when little is

known about a phenomenon, as it enables the perspectives and experiences of participants to inform the topic under investigation. The scope of inquiry is therefore not limited by a pre-determined frame of reference (Stebbins 2001). In the final phase of analysis, Critical Social Theory was adopted to interpret the overall themes.

Setting and Sample

Interviews were conducted with the EbEs who taught the co-produced module developed through the COMMUNE project in each partner site. Table 2 summarises the distribution of EbE by country and gender.

Insert Table 2 here

Procedure

An interview guide was developed with information from multiple sources: initial focus groups with service users, project learnings to date, review of the literature and the overall co-production process of the learning module. The interview guide provided some focus, yet also retained the flexibility to allow participants to contribute their thoughts and opinions that extended beyond the questions asked. The relaxed interview format encouraged participants to direct the content and focus on issues of importance to them.

Invitations were sent by email to the EbEs, providing information about the study and inviting their consent to be part of an in-depth individual interview (one group interview was held in Norway). Interviews were conducted by a researcher not immediately involved in the project to better facilitate open and honest communication.

Ethics

The research was approved by the relevant University Ethics Committee [details withheld to facilitate anonymous review] where applicable. No separate ethical clearance was required in the Netherlands, Finland or Norway. Potential participants had prior knowledge of the evaluation plan as members of the research team; however, they were fully informed about the study and reminded that participation was voluntary. EbEs could decline involvement, or subsequently withdraw their involvement during the interview process. Participants were advised that all data would be treated confidentiality. The Declaration of Helsinki guidelines were followed throughout the data collection process (World Medical Association 2013).

Data analysis

An exploratory design meant all EbE interviews were transcribed verbatim (n=9). Thematic analysis was undertaken at each university according to the data-driven, multi-phasic process outlined by Braun & Clarke (2006). All data were then pooled and re-analysed with Braun & Clarke's process to develop a refined set of themes from the entire data corpus. At the final stage of analysis, CST was used to interpret these themes.

Results

Two themes emerged from data analysis. The first reported how the EbEs unique approach of using personal narratives in their teaching resulted in increased relationality between EbEs and nursing students. Participants suggested that their relationship with students differed in nature to that observed between students and clinical lecturers. The non-didactic, human-to-human teaching approach created a more equitable power dynamic. The second theme indicated that, from the perspective of EbEs, the use of

personal narratives in teaching, meant students generally placed less emphasis on psychiatric diagnostics. EbEs found students had an enhanced understanding of the lived experience of clinical diagnoses and symptoms, and subsequently, the value of humanistic approaches to mental health nursing practice (e.g. empathic interpersonal skills). The quotes which demonstrate aspects of these themes are referenced with the country of origin (FIN = Finland, AUS = Australia, NLD = The Netherlands, NOR = Norway, IRL= Ireland – both sites, ICE = Iceland).

Theme one: There wasn't a barrier

A key difference from traditional clinical offerings was the EBEs use of personal narratives to augment learning. EBEs felt that sharing potentially stigmatising information (typically kept private) generated a richer type of classroom dialogue, both in terms of content and structure. EbEs reported that students were able to draw on their previous exposure to 'mental illness' and ask questions which could be considered taboo in clinical and professional settings. Sharing experiential knowledge on such a stigmatised topic appeared to create a less hierarchal structure to the learning experience than traditional clinician-led learning. EbEs saw the more horizontal power dynamic as a fundamental element of the teaching approach, and encouraged students to ask candid questions:

> I believe that the fact we were there as Experts by Experience and shared our stories, gave the opportunity to have openness with each other (NET)

> I put it out to them that I really wanted them to ask questions, you know if they had them - ask them…. I felt there wasn't a barrier then that they wouldn't ask a question. I want to enhance their education, I want to make them curious; I want them to ask more questions. (IRE)

EbEs reportedly moved away from traditional teaching methodologies, to develop a classroom environment that was authentic and allowed for discussions on power imbalances to be facilitated. Through using narratives as an educative tool, EbEs believed that they transcended the traditional classroom dynamic, allowing for a more personal approach which they suggested was appreciated by students.

> We made the decision not to use PowerPoint or be giving lectures… this was much more personal, and the students liked it that we did it that way (ICE)

> It [sharing experiences] is a more purist way of delivering it because it is from the heart and it is meant to be heart rather than head (IRE)

The personal delivery of the EbE teaching material provided a unique student-teacher dynamic and dialogue.

Theme two: Made the human being visible

EbEs reported that the use of personal narratives in their teaching offered both an unheard perspective and contextual information which is not otherwise available. Considered use of story provided intricate details on the lead up to seeking mental health treatment, the personal impact of that treatment and the multi-faceted recovery process beyond hospital admission. Students learned about other aspects of the individual's life (motivations, non-clinical aspects) which served as an effective reminder that people who access mental health services are human beings, with similar hopes and dreams as everyone else in the community. EbEs believed that it is rare for practicing mental health nurses to be privy to such personal background information before and after an episode of clinical care.

The EbEs reported that giving personal, contextual information painted a more complete picture of an individual as opposed to a diagnostic category often used to describe people in the mental health system. The personal delivery was described by two EbEs as a 'powerful' method to convey this humanity:

> The narrative of what happened and how it has turned out now, that has been a powerful learning for the students (IRE)

> I found it was quite powerful to give students these snapshots which were quite heavy in detail. So, like the size of the room and how it smelt and the white walls, white….and I find that helps students really imagine it… (AUS)

Narratives provided a more comprehensive picture of an individual's clinical presentation. Furthermore, EbEs believed that, by describing their experiences in rich detail, students could better imagine themselves in that vulnerable position, thus cultivating empathy and fostering critical reflection. As well as using narratives as a vehicle for learning, EbEs placed high value on understanding the background of each individual the students would support in their future nursing practice:

> We emphasised the importance of the life-history of those they met on the wards, how precious this story is and how good it is to be curious about the person, what happened to her or him…what is the story behind, not just the story of the illness but the life-history. We could notice that they became curious (ICE)

EbEs reported that the student focus on clinical classifications lessened during the COMMUNE module:

…. initially the students were going 'oh what is her diagnosis'… (IRE)

Students … towards the end of the course, had much less emphasis on diagnosing people with different conditions, which I was very pleased with. And they seemed to really understand what strength-based approaches were. And I think that is a very big change, because at the beginning of the unit, there was a request…when students were asked what sort of textbook they wanted, most wanted a textbook which had a chapter on each diagnosis. So…they changed their thinking about that. (AUS)

EbEs noticed students were more able to recognise those with a label of mental illness as multi-dimensional, and foremost, as people:

Students got a different view of their clients. They tried to approach them as human beings and not as a diagnosis or belonging to some patient-group (ICE)

We have made the human being visible, instead of being walking diagnoses. (FIN)

…they see the person rather than the illness (IRE)

Strong emphasis was placed on the individuality of people labelled with mental illness, regardless of their diagnosis:

I don't think you can get that from a book. Even if we have the same problems, we are different people. We can have the same diagnosis, but we are very different people behind those diagnoses (NOR).

The EbEs claimed that their description of their initial experience of powerlessness helped make students more aware about how they might respond in clinical practice. They also believed that students could learn the practical aspects of relational and interpersonal nursing practice, such as strategies for early therapeutic engagement, from an experiential perspective:

> I could tell them what helped me when I was hospitalised, which was not the least communications with the mental health nurses…they would ask us how we would like them to interact with us when we were hospitalised. (ICE)

In addition to practical communication techniques during periods of intense distress, the EbE teaching encompassed the unique trajectory of recovery, where individuals gradually increase their autonomy in a unique, non-linear healing process. EbEs reported that they were able to convey their humanity by being physically present in the classroom and providing contextual and practical information about their experiences:

> …in mental health care the development towards control by the patient is seen. The patient becomes more and more articulate, gets to decide more by themselves. It is wise that students get to know that side of patients early on (NET).

Discussion

The existing literature supports consumer involvement in mental health professional education, yet fails to describe the impact of its inclusion. The current study examines lived experience teaching in nursing education by applying Critical Social Theory (CST) to explore the contribution from the

perspective of the educators. Through the lens of CST, the findings suggest that the inclusion of EbE teaching created an opportunity for unique dialogue between students and EbEs, which offered an alternative perspective to traditional nursing education.

Liberation pedagogy, or emancipatory education, provides a useful lens in which to view this multi-faceted learning experience. This approach draws on the seminal work of Paulo Freire, who rejected the 'banking approach' to education, where students are 'tabula rasa' (empty vessels to be filled) by the knowledge of the educator (Freire 1970). Instead, Freire advocated for students to be active agents in the education process. The educator and students co-create knowledge through a dialogue (*there wasn't a barrier)*. The inclusion of EbE teaching meant students were introduced to tensions in the biomedical model through a similar dialogue where co-creation is possible. Incorporating teaching from a lived experience perspective was thought to be an effective means of fostering critical enquiry. EbE teaching appeared to add an emancipatory element to mental health nursing education and provided opportunity for students to develop a broader critical consciousness than available through traditional methods alone.

Viewing people who access mental health services as 'others', distinctly different from oneself, can be detrimental and inhibit a person-centred nursing approach. Sharing narratives is an effective means of challenging 'othering' (Duchscher 2000; Wolfensberger *et al.* 1972; Allport *et al.* 1954; Oliver 2013) as it shows the human commonalities between students and EbEs. EbEs in this study reported that they provided students with the opportunity to ask candid questions which would otherwise go unasked. Furthermore, EbEs outlined that learning from narratives provided an opportunity to learn about key social impacts of being labelled with mental illness, similar to other published research (Freire 1970; Pescosolido *et al.* 2010; Stuart 2016).

Recovery is not easily articulated in clinical texts and language (Byrne et al, 2014). However, EbEs in this study felt that exposure to narratives with contextual information, and the use of this information to illustrate concepts, gave students insights which cannot be provided through traditional teaching methods. EbEs also noticed that the focus of their students broadened from pure diagnostic/clinical criteria, to considering the perspective and background of the individual. The egalitarian dialogue with the EbE offered a view which typically included social marginalisation as well as personal experience of clinical care/recovery.

The scope of the EbE teaching included the various socio-political factors of their distress (e.g. poverty, racism, isolation, abuse). EbEs felt the unique combination of experiential and professional teaching encouraged students to move beyond a purely diagnostic mindset, to one which promoted humanistic nursing approaches; this has also been documented in other studies (Stuart 2016; O'Donnell & Gormley 2013; Byrne *et al.* 2013). The personal delivery through narrative provided rare opportunities for students to critique their own personal and discipline-specific values, encouraging critical thinking.

The stigma attached to mental illness is significant; however, it is addressed in only some of the formal clinical curricula in all countries involved in this study (Byrne *et al.* 2013; Byrne *et al.* 2014; McCann *et al.* 2009). Stigma has a pervasive and negative impact on all aspects of an individual's life. Some theorists view stigma as more disabling to an individual than any limitations from their health condition (Oliver 2013). It is common for people labelled with mental illness to internalise multiple negative social messages (Oliver 2013; Freire 1970). Freire claims the internalisation of stigma is intially expressed through self-depreciation, where individuals begin to believe the

stigmatised perceptions conveyed by others (Freire 1970; Wolfensberger *et al.* 1972).

Stigma is a major inhibitor of high quality care in mental health settings (Byrne *et al.* 2014), and a persistent feature of the lives of people who access mental health care (Corrigan *et al.* 2012). Biological explanations, such as the chemical imbalance theory, can covertly reinforce the view that people labelled with mental illness are fundamentally different from those who are not, thus deepening, rather than challenging stigma (Stuart 2016; Pescosolido *et al.* 2010). The omission of this significant topic means students can be unprepared for its manifestations in clinical practice (e.g. difficulty making referrals, derogatory language and therapeutic pessimism). Pervasive stigma/sanism means mental health nursing will always involve advocacy for the individual, with both external agencies and within the hospital setting. Effective advocacy must stem from respect for individual autonomy: it is difficult for a nurse to advocate effectively if they hold stigmatising attitudes towards the people they support (Ihalainen-Tamlander et al. 2016). EbE teaching in mental health nursing education created an opportunity to create new knowledge and interrogate existing value systems. Personal contact with people labelled with mental illness is proven to be effective in redressing stigmatised beliefs (Corrigan *et al.* 2012; Stuart 2016; Allport *et al.* 1954), and supports EbE teaching in contemporary mental health nursing education. At present there are no pedagogical frameworks tailored for EbE teaching, and the educators in the present study developed individual approaches to their work. This is worthy of exploration to further embed EbE contributions into the curricula.

The findings of the current study highlight how EbEs perceive their contribution to nursing education. The EbEs felt their teaching enhanced the students' understanding of mental distress and recovery journeys. While it is acknowledged that there is a need to progress past using 'storytelling'

exclusively as a way of involving EbE in nursing education, considered narratives can augment theoretical content and generate multi-dimensional understandings of clinical and social constructs.

Conclusions

The current study supports previous research indicating that incorporating first-hand lived experience teaching into nursing curricula broadens the scope of student learning (Byrne *et al.* 2014; Happell *et al.* 2014a). EbEs felt they offered a different source and type of knowledge and thus were a catalyst for deep learning experiences for students and a mechanism for countering hegemonic teaching practice. Narratives proved to be a 'powerful' method to convey the social context of being labelled with mental illness (Stuart 2016) and emphasise the 'human' behind the diagnostic label (Horgan *et al.* 2018). The lived experience perspective also provided students with education on salient aspects of recovery-orientated nursing care, such as building therapeutic connections and the importance of interpersonal skills.

Despite the significant impact of stigma/sanism (Stuart 2016; Oliver 2013; Byrne *et al.* 2013), on people diagnosed with mental illness, the entire topic is not addressed comprehensively in all pre-registration nursing curricula (Mental Health Nurse Education Taskforce 2008). In COMMUNE, the two domains of knowledge (phenomenological & academic/professional) operated in tandem to provide a more rounded and multidimensional educational experience. Students were more likely to see those who have accessed mental health services as individuals and not as diagnostic labels. The complementary knowledge sets have the potential to galvanise recovery-orientated nursing practice and further participatory policy goals.

It is important to acknowledge that the findings of this study represent the experiences of EbEs who delivered the module of learning and may not necessarily reflect the perspectives of the students.

Relevance to clinical practice

Nurses with the skills and knowledge to work collaboratively with consumers are pivotal in high-quality mental health services. EbE involvement in professional education has been identified as an effective strategy; to stimulate interest in mental health nursing and redress any stigmatised attitudes. Negative attitudes inhibit person-centred practice. Such a position undermines the therapeutic alliance, which is central to Recovery. Taken together, EbE teaching can make a significant contribution in shaping mental health curricula and pre-registration education to be more receptive to consumer needs. Future research could explore how to expand EbE contributions to maximise their input.

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Table 1. Co-production: Consumer-identified qualities of a skilled mental health nurse provided the frame for the COMMUNE module.

Focus group themes	Focus of module
Desired qualities of a mental health nurse	**Increased emphasis on…**
Respect towards service users as persons	Contact between service users and students
Empathy and compassion, non-judgemental approach	Self-reflection related to power, values and bias
Reduced emphasis on diagnostic assessment	Strength-based approaches
Effective communication skills	Communication skills
Ability to foster hope and believe that recovery is possible	Spending quality time with service users
Enhanced understanding of support options after episode of care	Local support services available

Table 2 – Number and gender of EbEs by country

Country	Number of EbEs	Males	Females
Finland	2	1	1
Australia	1	0	1
The Netherlands	3	2	1
Norway	3	1	2
Ireland (Dublin)	1	0	1
Ireland (Cork)	2	1	1
Iceland	2	1	1
Total			

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