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"There's more to a person than what's in front of you": nursing students' experiences of consumer taught mental health education.

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"There's more to a person than what's in front of you": nursing students' experiences of consumer taught mental health education

Abstract

Holistic and person centred nursing care are commonly regarded as fundamental to nursing practice. These approaches are complementary to recovery which is rapidly becoming the preferred mode of practice within mental health. The willingness and ability of nurses to adopt recovery-oriented practice is essential to services realising recovery goals. Involving consumers (referred herein as Experts by Experience) in mental health nursing education has demonstrated positive impact on the skills and attitudes of nursing students. A qualitative exploratory research project was undertaken to examine the perspectives of undergraduate nursing students to Expert by Experience-led teaching as part of a co-produced learning module developed through an international study. Focus groups were held with students at each site. Data were analysed thematically. Understanding the person behind the diagnosis was a major theme, including sub-themes: person-centred care/ seeing the whole person; getting to know the person, understanding, listening; and, challenging the medical model, embracing recovery. Participants described recognising consumers as far more than their psychiatric diagnoses, and the importance of person-centred care and recovery-oriented practice. Understanding the individuality of consumers,

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their needs and goals, is crucial in mental health and all areas of nursing practice. These findings suggest that recovery, taught by Experts by Experience is effective and impactful on students' approach to practice. Further research addressing the impact of Experts by Experience is crucial to enhance our understanding of ways to facilitate the development of recovery-oriented practice in mental health and holistic and person-centred practice in all areas of health care.

Keywords:

Consumer academic

Consumer participation

COMMUNE

Education of health professionals

Experts by Experience

Mental health

Mental health nursing

Recovery

INTRODUCTION

Nursing distinguishes itself from other health professions as the provider of holistic and person-centred care (Jasemi *et al.* 2017; Tatsumi 2017; Byrne *et al.* 2013a; Santangelo *et al.* 2018). Holistic and person-centred care tend to be used interchangeably to describe an approach to practice which recognises the person as a whole entity, far greater and more complex than their presenting illness or injury. Person-centred care therefore extends beyond symptom management and treatment to addressing broader psychosocial needs and concerns considered equally important to medical

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treatment in restoring health (Kennedy 2017; Hornik-Lurie *et al.* 2018; Goodrich 2016; Santangelo *et al.* 2018).

Person-centred care is particularly relevant for nursing, as it is the largest profession within the health care system, and generally enjoys the closest relationship with consumers of services (Australian Institute of Health and Welfare 2018; Shamian 2016; Ministry of Health 2016; Office of the Nursing and Midwifery Services Director 2012; Holm & Severinsson 2011). Nurses are also considered educationally prepared to provide biopsychosocial care (Byrne *et al.* 2013a; Santangelo *et al.* 2018; Holm & Severinsson 2011). At the same time, nursing practice is often criticised as subordinate to, and dependent on, medicine and subsequently concentrating more on biomedical aspects of care (Santangelo *et al.* 2018; Schout & de Jong 2017). This criticism has deepened in countries where undergraduate specialist mental health nursing programs have been abolished, and underrepresentation of mental health nursing content in undergraduate programs has been the outcome (Happell & Cutcliffe 2011; McAllister *et al.* 2014; Råholm *et al.* 2010). Following a review of nursing curricula in Ireland, it was recommended that direct entry into the four disciplines of nursing should remain. This in part was to ensure sufficient numbers of graduates in areas such as mental health, intellectual disability and children's nursing, particularly in light of the serious workforce implications following the abolition of undergraduate specialisation seen in countries such as Australia (Department of Health 2012).

Mental health services require a nursing workforce with the capacity and desire to work collaboratively with consumers (Santangelo *et al.* 2018). The more recent policy emphasis on recovery has influenced the strongly medical approach, with greater emphasis on consumers directing their own care and treatment (Commonwealth of Australia 2013; Byrne *et al.* 2015; Boumans *et al.* 2016; Health Services Executive 2018). A person-centred

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approach is essential for recovery-focused practice; however nurses identify the medical focus on signs and symptoms as a major barrier (Cusack *et al.* 2017; Hornik-Lurie *et al.* 2018).

Barriers to recovery-oriented practice need to be addressed to provide high quality mental health care. The limited literature suggests generic, non-specialist undergraduate nursing programs are unlikely to equip students with these skills given the limited attention to mental health nursing generally provided in these programs (Happell & Cutcliffe 2011).

Furthermore, recovery has been described as a 'lived experience discipline', developed through the consumer movement as an approach that emphasises strengths, autonomy and hope, in contrast to the medical model focus on illness, symptoms and deficits (Byrne *et al.* 2015). As a 'lived experience discipline', it is argued that recovery should be taught by consumers, as the originators of that knowledge (Byrne *et al.* 2015). Indeed it is argued that recovery has been colonised by health professionals as a model of practice, often without recognition of its origins within the consumer movement (Byrne *et al.* 2015; Edgley *et al.* 2012).

The active and genuine involvement of consumers in the education of health professionals would therefore seem a potential strategy to enhance nursing students' understanding of recovery and acknowledge it as consumer expertise. Consumer involvement in health professional education has been identified as valuable and effective (Schneebeli *et al.* 2010; Scammell *et al.* 2016; O' Donnell & Gormley 2013; Happell *et al.* 2015; Byrne *et al.* 2014; Happell *et al.* 2014a; Horgan *et al.* 2018; Happell *et al.* 2018; Arblaster *et al.* 2015; Mahboub & Milbourn 2015; Ridley *et al.* 2017; Goossen & Austin 2017; Gordon *et al.* 2014). Consumers as educators and academics have demonstrated the development of more positive attitudes amongst health professionals towards people labelled with mental illness as an

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outcome of their involvement (Byrne *et al.* 2013a; Ridley *et al.* 2017; Goossen & Austin 2017; Byrne *et al.* 2013b).

Unfortunately, more favourable outcomes have not led to a substantial increase in consumer participation. Most participation is still ad hoc and limited to short sessions as guest lecturers (McCann *et al.* 2009; Happell *et al.* 2015). The potential impact consumer involvement might make is therefore not being fully achieved.

An international study named COMMUNE (Co-production of Mental Health Nursing Education) was designed to contribute to the evidence-base for consumer involvement in nursing education. The aim of the project was to develop a mental health nursing unit of study, co-produced by Experts by Experience (EBE) and Nurse Academics. The study, conducted in six countries (Iceland, Ireland, Norway, Finland, the Netherlands and Australia), involved a comprehensive evaluation of this initiative, including qualitative exploration of students' experiences of the co-produced unit, and being taught by EBE.

A note on language.

The consumer members of the COMMUNE project chose Experts by Experience (EBE) to describe their role in the project, thus EBE is the term used in this paper. When describing people labelled with a mental illness and/or using mental health services more generally, we are using the term consumer. Consumer is the language of policy in Australia, where this component of the research was coordinated. Consumer is often used interchangeably with service users, the term more commonly used throughout Europe.

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Aim:

The aim of this paper is to explore nursing students' experiences of EBE led mental health nursing education. *Understanding the person behind the diagnosis* was a major theme developed through the data analytic process and is the topic presented in this paper.

METHODS

Approach

This research was conducted using a qualitative exploratory approach. Qualitative exploratory methods are indicated for topics of interest where little or no research has been conducted (Stebbins 2001). Qualitative exploratory research enhances the capacity of the research participants to shape and inform the topic of inquiry, compared to methods that pre-determine the scope (Stebbins 2001). The project was co-produced between nurse academics and EBE, making the need for a flexible design, capturing and utilising the skills and expertise of all team members, even more important.

Setting and sample

This international research project was conducted in seven universities from six countries Australia, Iceland, Ireland (Cork and Dublin), Finland, the Netherlands and Norway. Target participants were students undertaking an undergraduate nursing program in these universities, who were taught the co-produced learning module by an EBE as part of the Commune project. Students from the Irish universities were undertaking a specialist program of four-years duration in mental health, leading to a specific qualification in mental health nursing. Students from the other five universities were

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completing a generic program, three or four years in duration. On completion, students from generic programs were eligible for registration as a nurse without specialisation in an area of nursing practice. The students were required to complete one or more mental health nursing subjects as part of this program.

Students who had been taught by EBE as part of the COMMUNE project were invited to attend a focus group. Information about the research was provided during their classes and advertisements were sent via email and message boards, and displayed in prominent locations. Eight focus groups were held, with a total of 51 students. More information about student participants is presented in Table 1.

Insert Table 1 here

Procedure

To provide some structure and consistency for the focus groups, an interview guide was developed to ensure topics relevant to the research study were considered, and to enhance conversation flow and discussion. Participants were not restricted to topics covered in the interview guide, and were encouraged to discuss experiences and issues they considered relevant. The focus groups were digitally audio recorded and transcribed to facilitate data analysis.

Ethics

Prior to commencing the research, ethics approval was obtained at each participating University. A full explanation of the research and requirements for participation were given to interested students. They were advised their participation was on a voluntary basis and the decision not to participate

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would not impact on their study progress. A Plain Language Statement was provided and students were requested to read this carefully. Questions from students were encouraged. Those students who retained their interest were provided a consent form to sign. Participants were assured that all data would be treated confidentially and publications would include aggregate data only.

Data analysis

As an international project, data analysis involved two stages. In the first instance each university analysed data they collected. Analysis was independently conducted by at least one EBE and one nurse academic at each site. The Braun and Clarke (2006) framework for thematic analysis was utilised to ensure consistency of approach.

The Braun and Clarke (2006) framework provides a structured and thorough process for identifying themes through the research process. Researchers utilised the following stages in conducting their analysis:

- Transcripts were read and re-read several times to assist researchers to become familiar with the content and its underlying meaning.
- Codes were assigned as labels to particular areas of content.
- Codes were examined and considered for their relevance to the broad research focus and the specific aims
- Identified codes with similar content were grouped together to identify provisional themes
- Provisional themes were organised into a conceptual map
- The themes were carefully re-examined for relevance and accuracy
- Transcripts were re-read to ensure no relevant data had been missed

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Each university team met to review and discuss the analysis in terms of process and outcomes. Independent analyses were compared and differences were considered and modified until consensus was established. All data sets were then sent to the lead university for this component of the research. The complete data set was analysed using the same process to ascertain the major themes across all settings. It was particularly important to ensure EBE researchers had equal input into the data analysis process as nurse academics. The final product reflected these unique and diverse perspectives and ensured fidelity with the principles of co-production, as well as enhancing the rigour and relevance of the research findings.

FINDINGS

Understanding the person behind the diagnosis.

A major theme to emerge from the student focus groups was: recognising the person and identifying each one as an individual with needs and strengths that extend far beyond their diagnosis. Student participants described having a greater understanding of the person after being taught by EBEs. This theme encompassed three subthemes:

- Person-centred care/ seeing the whole person
- Getting to know the person, understanding, listening
- Challenging the medical model, embracing recovery

These findings are now presented and supported with indicative quotes from the participants.

Person-centred care/seeing the whole person

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One of the most significant lessons learned from the participants' interactions with EBE was the importance of person-centred care. This involved seeing the person as much more than a diagnosis or a presenting problem and understanding them within the broader context of their lives, and responding accordingly:

> "There's more to a person than what's in front of you… I think we get our blinkers on sometimes … it always comes down to looking … there is a person beneath there (Australia).

> The experiences made me think to remember that the person isn't their disorder, they are human (Iceland).

> People with mental health problems are ill just like people with somatic illness … They are like us no difference (Finland).

Being taught by EBE and hearing about their experiences first hand strongly influenced many participants. Through these experiences, they felt better able to understand the consumer's experiences and to develop respect for them as a person, essential ingredients for person-centred care:

> [I] will probably … think a bit more … about - the patient's side … in a way it is still with us what they told about how they experienced things … [I will] at least try my best to be a good nurse and a support for the patients. … User [consumer] … involvement, is incredibly important … a fellow human of equal worth … meet the patient on the same level (Norway).

> We need to be thinking of people in the perspective of, if this was your friend, your dad or mum or any of your relationships how would you want them to be treated and I think the sessions made you conscious of the person (Iceland).

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To provide person-centred care it was understood that nurses need to understand the complexities consumers experience that may pose a barrier to seeking help. One participant describes reflections on a particular situation in clinical practice and how she would approach it differently using the insights gained from learning from EBE:

> I think now as a nurse I'd be going in and finding out, all right does she need maybe a consult from another team to see what's going on here? … even the physio was angry at her because of, like, she's just lazy, she won't do this and that, but she was in so much pain … no-one looked beneath what they saw ... now I would definitely do a lot more different things. I'd probably be asking for help from other areas … finding out what actually happens at home, because she kept saying there were so many more things she could do at home, so there was something going on (Australia).

The experiences and knowledge gained from interacting with EBE had also highlighted for some participants the tendency for nursing practice to be focused on tasks as the priority, rather than on the needs of individual consumers:

> Often you're too focused on doing what you need to do ... as a nurse, I need to learn all these tasks so that's going to be my focus … And I worry that's detracting from the type of nurse I want to be because we have to put a lot of time into learning skills rather than the patient-centred care, which is why I wanted to become a nurse in the first place (Australia).

Getting to know the person, understanding, listening

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Individuality, and its association with recovery-orientated care was viewed as vastly different to the medical view of illness, with its limited person-centred focus. It was acknowledged that a relationship needs to be developed with the person as he or she presents rather than as described through diagnostic information appearing in their case notes. This would enable nurses to understand the person at the human level rather than the medical level:

> No matter what is documented about a patient … you actually see the whole person, and maybe see what the actual problem is, and not make any assumptions … meet the person … with an open mind, no matter what (Norway).

Some participants described how the involvement of the EBE had highlighted the importance of communication as essential for the effectiveness of knowledge:

> I thought that knowledge was very important. And I've learned that knowledge is not worth anything if you do not know how to bring that across (the Netherlands).

An important lesson described by some participants involved the need to look beyond the obvious and not assuming how consumers appear is reflective of how they really feel:

> there's more beneath the surface … I could be sitting here talking to you and who knows what's going on in your life … or your mind – you're portraying something else (Australia).

> She [EBE] really helped us get a perspective … you are going to delve deeper than just the surface. … This person isn't just a label … there is a

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lot more behind that, like what did they go through to get here today (Iceland).

Another development in learning, gained from experiential education, was an ability to connect the concept of empathy to practice. Reflecting on the EBE narratives, and the broader context of their lives allowed students to understand how they might begin to forge empathic relationships with consumers:

> I think it just gives more insight into what they might be going through … obviously we can't feel their pain but we can have a little bit of insight into what's mainly going on with them (Cork, Ireland).

Challenging the medical model, embracing recovery.

The experience of being taught by EBE had changed the way many students viewed mental health service delivery and the approaches to education they had experienced to-date. Traditional biomedical care, with an emphasis on diagnosis and medication, was generally portrayed as the dominant model for mental health service delivery. However, the limitations of this model were understood, in the context of the individual's unique recovery experience:

> "So we – especially in mental health … focus on a little bit more diagnosis, the specialised treatments … you'd be looking for exhibiting symptoms and medications that you think might help, but the thing is they're an individual. They might have tried that; that might not work for them, and they're not always going to tell you that (Australia).

This change in thinking about approaches to care and treatment was noted by some participants as relating specifically to being taught by an EBE:

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> I felt I became more critical of the methods used at the hospital . . . It [being taught by the EBE] got you to think more about why things are done as they are done (Iceland)

> She [EBE] really empowered me to want to be more and educate myself more around clients and how they actually feel within the services rather just being concerned by the medical model or the nursing model (Dublin, Ireland).

The EBE teaching experience encouraged an understanding of and an appreciation for recovery-orientated practice as an overall guiding philosophy within mental health nursing. This was seen in contrast with how they conceptualised care, prior to the delivery of the EBE-led module:

> I would have thought the whole thing about mental health nursing being honest before was that we had to understand the conditions; I didn't think we'd have to an extent have as much an influence on their [consumers'] recovery (Cork, Ireland).

Learning more about recovery from EBE encouraged many students to understand how the current system tends to focus on the illness model. By contrast they came to understand that recovery was more about quality of life than the medical model:

> We all have something to give and that recovery thing, holistically it's not about pinpointing the sickness, it's about being together and helping people experience the best life they can have for themselves that they're happy with. Looking at the other side of the coin (Australia).

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Focusing on strengths rather than deficits, encouraged students to question the role of the medical model in mental health care and treatment, sometimes quite critically. As one student eloquently stated:

> I don't know if mental illness is really mental illness … A lot of the things are different personalities, different strengths, and there's so much more there than that someone is sick for ever and ever. I … feel like we need to embrace the differences rather than see them as a problem to be dealt with, because we've all got our strengths and weaknesses and yes, there are some things that can really affect someone's life, but they can also use those things to create amazing things to happen, so for me that's really spun that around in my mind, that's what I got from it (Australia).

DISCUSSION

As mental health services aspire to a stronger recovery focus, with more emphasis on individuals directing their own care and treatment, nurses have an important role in promoting change through recovery-oriented practice (Santangelo *et al.* 2018). Participants described becoming critical, through learning from the EBE, of the narrow focus of the medical model while developing an increased understanding of recovery and its relevance to people accessing mental health services. The medical model is presented in the literature as a major barrier to recovery-oriented practice (Santangelo *et al.* 2018; Cusack *et al.* 2017). Recovery-focused approaches to nursing practice have been articulated (Hornik-Lurie *et al.* 2018; Santangelo *et al.* 2018), however nurses need a clear understanding of recovery and recovery-oriented practice to translate ideals into reality (Cusack *et al.* 2017).

Training of the mental health nursing workforce has thus far been identified as a strategy for preparing nurses for recovery-oriented practice (Zuaboni *et al.* 2017; Gee *et al.* 2017; Walsh *et al.* 2017; Hornik-Lurie *et al.*

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2018). Evaluations suggest training has a role in influencing attitudes; however published evaluations to-date have been limited and inconclusive (Gee *et al.* 2017; Hornik-Lurie *et al.* 2018), and the impact of attitudinal change on practice is not known or well understood.

Findings from the current study suggest students' experience of the COMMUNE project has resulted in more positive attitudes towards and enhanced awareness of person-centred and recovery-oriented practice. Similar findings were derived from qualitative research undertaken with undergraduate nursing students completing a major stream in mental health nursing in an Australian university (Byrne *et al.* 2013b). This study demonstrated students' perceptions that their improved attitudes towards, and greater comprehension of, mental illness was a direct result of the lived experience-based teaching. Furthermore, student participants identified that understanding recovery had facilitated their understanding of the concept of holism, which they had previously found difficult to grasp (Byrne *et al.* 2013a). Holism is identified as a complex concept, lacking clear definition and therefore often not well understood (Jasemi *et al.* 2017). EBE-led teaching might therefore play a crucial role in augmenting nursing students' understanding of holistic care and by association their understanding of person-centred practice.

Most nursing students, on graduation from generic nurse training, will choose to practice in health care settings other than mental health (Bingham & O'Brien 2018; Thongpriwan *et al.* 2015; Happell *et al.* 2014b; Stevens *et al.* 2013; Ong *et al.* 2017; Hunter *et al.* 2015; Happell & Gaskin 2013; Edward *et al.* 2015). The high prevalence of mental illness and mental distress across the health care sector (Jayatilleke *et al.* 2018; Giandinoto & Edward 2015; Garrido *et al.* 2017; Bahorik *et al.* 2017), highlights the importance of positive attitudes for nursing students irrespective of where they choose to practice. Outcomes from the current study extend the findings of Byrne and colleagues (2013b; 2013a). Participants had chosen to undertake a major in

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mental health nursing and given they were attracted into this field, more positive attitudes might therefore be presupposed. Students in the current study (undertaking both specialist and generic programs) appear similarly influenced by EBE-led teaching. This is a positive finding. Recovery has been identified as a lived-experience discipline (Byrne *et al.* 2015), education directly based on, and delivered via lived experience enhances the authenticity and enables students to understand it well beyond theory. This premise is supported by the findings of the current study.

Participants identified the importance of establishing a relationship with the consumers they work with, getting to know them as people, listening and understanding rather than automatically making judgements or decisions about their care and treatment and utilising this enhanced understanding of the person behind the diagnosis to ensure person-centred care and recovery-focused practice. Relationship building and therapeutic interactions are identified as essential mental health nursing skills (McAllister *et al.* 2014; Santangelo *et al.* 2018), and indeed are relevant for all areas of nursing practice and therefore essential components of nursing education (Kourkouta & Papathanasiou 2014).

There is a paucity of consumer perspectives on the desirable characteristics of mental health nurses found in the literature. This is a glaring omission given the focus on recovery, which by definition must be consumer driven. Effective communication and supporting recovery have been identified as essential components of mental health nursing practice (Gunasekara *et al.* 2014; Aston & Coffey 2012; Horgan *et al.* 2018) lending further support to the findings of the current study. Of particular interest is a recent international, qualitative exploratory study of consumer's views about the contribution EBE could make to mental health nursing education (Horgan *et al.* 2018). This research, co-produced between EBE and mental health nurse academics, identified two main themes: enhancing students'

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understanding of recovery by observing the 'human' behind the diagnosis and the importance of communication skills. These two themes were consistent across all countries and further enhance the applicability of the current findings: that EBE can make a significant contribution to achieving recovery-oriented practice within service delivery.

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Strengths and limitations

Further to the findings from this research and their relevance to the broader literature, this research has two main strengths: firstly, as an international study it broadens perspectives beyond the current literature base which is largely from Australia. Secondly, and probably most importantly, this research is the first known to evaluate the value of EBE-led learning through a co-produced approach. Co-production ensured the rich experience and perspectives of EBE were influential throughout the research and therefore enhances the validity and relevance of the research (Pinfold *et al.* 2015). Notwithstanding the identified strengths, the relatively small number of participations limits the generalisability of results and suggests the need for further research.

CONCLUSIONS

Contemporary mental health service delivery requires a change in nursing practice that is less dependent on the medical model, and more person-centred in focus. The pervasive medical model presents significant challenges for recovery-oriented practice and interventions are needed to overcome this barrier and contribute to practice change. The findings presented in this paper suggest involving EBE in mental health nursing education can contribute to an enhanced understanding of the person behind the diagnosis, the associated need for high level communication skills

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that forge emphatic relationships and the recognition of the broader strengths and needs of people accessing mental health services. While recovery is the paradigm in mental health, holistic or person-centred practice are central to all areas of nursing practice. These research findings suggest nursing practice in all health care settings may also be enhanced by this innovative approach to nursing education.

RELEVANCE TO CLINCAL PRACTICE

The extent policy goals for recovery focused mental health service delivery are realised will depend significantly on the capacity and willingness of the mental health workforce to embrace recovery concepts. Nursing as the largest professional workforce in mental health has an important role to play in adopting and promoting recovery-oriented practice. The recovery movement was led by consumers and therefore by definition, the discipline of recovery teaching must be led by consumers. EBE involvement in education is therefore crucial for recovery-focused mental health nursing practice.

Co-producing mental health nursing education with EBE is key to broadening nursing students' perspectives beyond a medical model focus and encouraging them to view the person as a whole that extends well beyond their diagnosis and presenting symptoms. As important as it is for mental health settings, the relevance of this research in promoting holistic and person-centred practice extends across the health care sector to all areas of nursing practice.

	Male	**Female**	**Total**
Finland	2	8	10
Australia	1	5	6
Netherlands	1	4	5
Norway	0	2	2

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Ireland (Dublin)	0	3	3
Ireland (Cork)	3	19	22
Iceland	1	2	3
Total	8	43	51

Table 1: Focus group participants

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