Working with Families Affected by Mental Distress: Stakeholders perceptions of Mental Health Nurses Educational needs.

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Abstract

Family and informal caregivers provide a substantial amount of care and support to people who experience mental health problems. The aim of this study was to explore mental health nurses', students' and service users' perceptions of the knowledge, skills and attitudes that are required by mental health nurses to work with families and carers using a qualitative methodology. Three themes emerged from the data: Knowledge of the family and how mental distress affects the family; Working with the family – support and education and Valuing the role of the family. The three themes demonstrate the complexity of preparing mental health nurses to work with families and carers and the paper offers recommendations about how this might be achieved.

Introduction and Background

The move to community orientated mental health care has meant that a greater emphasis is now placed on family involvement and the provision of informal networks of support for mental health service users. In addition, the utilisation of informal support networks including the family is advocated as part of the drive for more recovery-orientated services. It is recognised that families and other informal carers provide an enormous amount of support for people who experience mental distress (Expert Group on Mental Health Policy, 2006), be it emotional, practical, or financial. In fact, the reality is that for many users of mental health services, families are often the main source of support outside mainstream services. Despite this, there has long been a tension between family members and the providers of mental health services. This has meant that family members who are affected by mental distress often struggle to make sense of what is happening and experience a lack of information and support from mental health nurses. In addition, carers perceive that they are not recognised or appreciated for the role they have supporting family members affected by mental distress (Cree et al., 2015). While family involvement is advocated by mental health and social care policy, there is evidence to suggest that it is not routinely implemented across mental health services (Eassom, Giacco, Dirik, & Priebe, 2014; Cree et al., 2015).

The impact of mental distress on the family has been well described in the literature and the concept of burden of care has been used extensively to describe the emotional, psychological, physical and economic effects on families caring for a person with mental illness (Awad & Voruganti, 2008). Families may also be subjected to negative stereotypes, which may lead to discrimination, a sense of shame and being blamed for their relatives' mental health problems (Corrigan & Miller, 2004). In addition, subjective experiences of stigma and difficulties navigating the mental health services may result in the families experiencing difficulties with interpersonal interactions with mental health nurses, which in turn results in a lack of interest in their concerns about their relative and an inadequate flow of information about treatment and other processes (Angermeyer, Schulze, & Dietrich, 2003). According to Allerby et al., (2015) the experience of stigma is also associated with an increased sense of burden.

A recent survey conducted by the European Federation of Associations of Families of People with Mental Illness (Vermeulen et al., 2015) assessed the experiences of family caregivers across twenty-two countries. The survey found high levels of stress, depression and worry among the respondents (n=1111), which negatively impacted on their physical health (Vermeulen et al., 2015). In addition, the respondents were critical of the information they received from mental health professions and many felt that they were excluded from important decisions and were not taken seriously (Vermeulen et al., 2015). Regarding mental health nursing, the survey found that one in three respondents were dissatisfied with the support they received from nurses.

While the sample size in the Vermeulen et al., (2015) survey is relatively small given the diversity of the respondents, the findings do support several reviews that have been conducted about the experiences of families caring for people with mental health problems (Maurin & Boyd, 1990; Loukissa, 1995; Baronet, 1999; Saunders, 2003; Schulze & Rossler, 2005; Awad & Voruganti, 2008). Literature exploring the impact of mental health problems on the family includes the experiences of spouses, siblings, children and friends of the

person with a mental health problem and provides evidence of the effects described earlier (Tweedell et al., 2004; Wade, 2006; Schmid et al., 2009; Tranvag & Kristoffersen, 2008; Small, Harrison, & Newell, 2010; Hedman-Ahlström, Skarsater, & Danielsson, 2011; Ali et al., 2012; McAndrew et al., 2012; Wilson, Cruickshank, & Lea, 2012). To a lesser extent, positive experiences have also been reported. For example, Tranvag and Kristoffersen (2008) suggests that over time, the participants in their study experienced a sense of personal growth from the informal caring experience. In addition, over half of the respondents in Vermeulen et al.'s (2015) study reported that they discovered inner strength from their care giving experiences. Given these experiences, supporting families and other informal carers is essential to the implementation of recovery-orientated services and correlates with the espoused vision of mental health nurses as providers of holistic care.

According to Goodwin and Happell (2007), the participation of the family in mental health care delivery is dependent on the commitment of mental health professionals to make this a reality**.** They suggest that mental health nurses are in a pivotal role to foster an environment for involvement and to encourage and promote participation (Goodwin & Happell, 2007). However, there is a paucity of literature that describes effective and harmonious relationships between families and mental health nurses. In fact, much of the literature appears to describe mental health nurse's difficulty in meeting the needs of families when they are encountered. For example, Happell and Goodwin (2008) describe systematic barriers such as the availability of time, hampering the participation of families in the provision of care for mental health nurses. However, there was a clear recognition that provision of information (psychoeducation) was essential for families and part of the nurse's role. Blomqvist and Ziegert (2011) suggest that the centrality of the relationship between the nurse and the service user and the lack of professional autonomy were also cited as barriers to effective family involvement. Furthermore, the lack of clarity about information about the service user that could be shared with family members posed a challenge for mental health nurses (Blomqvist & Ziegert, 2011). While the experiences of

family members have been well documented and there is evidence to support the difficulties that exist for mental health nurses, there is less clarity about how better relationships and more active involvement between the two can be achieved.

To this end, a consortium of nursing faculty staff in six European Universities across five countries, came together in 2013 to design eLearning materials as part of an EU funded project entitled eMenthe. The central aim of the project was to enhance Masters level mental health nursing knowledge across three predetermined themes; 1) Recovery 2) Mental Health Promotion and 3) Families and Carers. The main purpose of the project was to offer standardised eLearning materials through open access to mental health nurses and other interested parties, which were based on consultations with key stakeholders in the area and critical reviews of the literature. The aim of this paper is to present the findings of the exploratory consultations that were held with stakeholders to ascertain the knowledge, skills and attitudes that are required by mental health nurses to work with families and carers.

Methods

The three themes which underpinned the eLearning materials were chosen following discussions among the mental health nurse faculty staff involved in the project. From the beginning, it was decided that key stakeholders, namely MSc in mental health nursing students, senior nurses from clinical and managerial backgrounds and service users including representatives from family and carer organisations would be consulted to inform the eLearning materials. An exploratory qualitative descriptive design using both individual interviews and focus groups was therefore seen as the most appropriate approach to the consultations, which were to take place in each of the partner sites across the five participating countries. A semi structured interview guide was developed which sought to establish the knowledge, skills and attitudes that were perceived as important to inform mental health nursing practice when working with families and carers. In addition, a lifespan approach was adopted which sought to situate the knowledge, skills and attitudes required from a child and adolescent, adult and older person perspective. A volunteer

convenience sampling strategy was adopted and a combination of strategies were used to recruit participants. This involved distributing information sheets to interested parties or using gatekeepers to recruit participants where appropriate. Ethical approval was obtained in all the partner sites and participants were required to give written informed consent. Where interviews and focus groups were audio recorded, they were transcribed verbatim. In other instances, field notes were written which were then used for the analysis.

Data Analysis

Data from the transcripts and the field notes were subjected to a conventional content analysis as described by Hsieh and Shannon (2005). This was considered appropriate, as it was not the intention of the analysis to develop theory but to describe the data in terms of the knowledge, skills and attitudes that mental health nurses to work more effectively with families and carers. Data pertaining to each of the respective themes was sorted following transcription. This involved merging the data from the different participants. At this point the data were read and reread and codes were assigned to the data and themes were identified. The themes were then further broken down into knowledge, skills and attitudes although there was some overlap. Finally, each theme was screened to ascertain its place on the lifespan continuum and themes were assigned based on their ability to flesh out these predetermined codes. Data were analysed using this approach in each country and then pooled together where it was amalgamated by one of the partner sites leading the analytic process. Once this process was completed, all partners from the respective sites reviewed the final analysis to ensure that it reflected their respective findings.

Results

Table 1 (Doyle et al., 2017) presents the number of people who participated in the research across the various countries involved. In total, there were 37 MSc in Mental Health students, 49 senior mental health nurses from a clinical a clinical and managerial background and 23 service users and representatives from family and carer organisations representing a total sample of 109 participants across 5 countries and the six partner sites. The analysis culminated in the emergence of three main themes:

1) Knowledge of the family and how mental distress affects the family.
2) Working with the family – support and education
3) Valuing the role of the family

[Insert table 1 here]

Knowledge of the family and how mental distress affects the family.

There was consensus across all the stakeholders that mental health nurses needed to have knowledge about the importance of the role of family and other informal caregivers in supporting service users. The participants talked about this in terms of mental health nurses having an 'awareness' and an 'understanding' of the role of the family and how this was the basis for the provision of support. To achieve this required knowledge about family systems and how mental distress influenced family dynamics and patterns of interactions within the family. The participants also talked about the importance of having knowledge to support and educate families but there was a sense that this knowledge needed to be underpinned by a theoretical framework that equipped mental health nurses with interventions that were evidence based. This knowledge was broadly couched within family therapy and other psychotherapeutic therapies. This theoretical knowledge could then be used to recognise stress within the family and interventions could be planned accordingly. In addition, it could be used to enhance communication within families. However, provision of support was also contingent on knowledge in other areas, such as expressed emotion, carer burden and courtesy stigma, and how to manage these was also perceived as important. Within this theoretical knowledge, some of the senior mental health nurses and the MSc students mentioned specific approaches to working with the family including open dialogue (Seikkula & Olsson, 2013; Seikkula, Alakare, & Aaltonen, 2011), solution focused therapy, cognitive behavioural therapy and dialogical interaction.

While the theoretical knowledge was important, the participants also talked about more practical and applied knowledge that mental health nurses could use to provide support to families. This centred on knowledge of what families

affected by mental distress need and the knowledge of the services and resources that are available to support families, which are provided by both statutory and non-statutory organisations. In addition, the participants suggested that mental health nurses need to be knowledgeable about the ways those families can assist service users to manage their mental health needs and at the same time as looking after their own mental health. It was perceived as imperative that nurses anticipate the family's needs during what might be a stressful time and provide confident knowledge of symptoms, medications and medication management that was explained in a way that was easily understood by the family at this time. This is highlighted in the following quotation:

> They [mental health nurses] should have information on the support available for carers and how to access those services. But they should have also evaluation skills; right kind of support at the right time, understanding on what kind of support is needed and when. Situation is very different if a family member has a just got the diagnosis or if there is a long history already.

Furthermore, the participants believed that when working with the family, mental health nurses also required knowledge on how to provide sensitive care to people. There was also a range of policy, legal and ethical knowledge that the participants believed that mental health nurses should possess. Policy related to an awareness of the national and international policy context where mental health nurses work. Legal issues were concerned with knowledge of the rights of the service users but also how these rights juxtapose with the rights of the family. This legal knowledge overlapped with ethical issues and was related to knowledge about confidentiality issues and the sharing of information that was sensitive but of concern to both service users and their family. Finally, there was also reference to mental health nurses understanding and being aware of the challenges associated with working with the family. Some of these points are highlighted in the following quotation:

> I think looking at mental health nurses, at first they need to understand the rights of service users. And this is complicated because you have to negotiate whether people are willing to engage with families or not. And then what do they do, if the

> service-user, the person who is the focus of the attention doesn't want to be involved. It's really, really tricky situation.

Working with the family – support and education

The second theme related to the skills needed by mental health nurses to work with families. Participants across all stakeholder groups suggested that skills to support and educate families were essential. In addition, participants mentioned that skills to work with children were also important. While there was some detail about these skills mentioned earlier, the skills discussed by the participants were mainly generic and included a wide range of communication and interpersonal skills such as respect, empathy, sensitivity, tact, and facilitation skills. Furthermore, the participants suggested that mental health nurses required diplomacy skills and skills to work effectively with groups.

Other generic skills such as assessment were talked about and the idea of diversity was built on with participants suggesting that recognising and working with family diversity were important skills. One of the MSc student groups brought in recovery-orientated approaches and talked about being able to 'instil' hope in families affected by mental distress. More specific to the family, the MSc students suggested that an essential skill for mental health nurses was helping families to navigate the system, which is linked to their knowledge about the mental health services and other resources available. Stakeholders from service users and family organisations spoke about the family and the service user as a unit and spoke about how mental health nurses need skills to bring the family together and help families to be supportive rather than controlling. This is exemplified in the following quotation from a service user.

> The biggest thing from a service-user perspective is that they want families to be supportive and not controlling. I think bringing families together is important. I think service users access to other service users. Service user spaces where people have a chance [to come together].

The skills required here were being able to balance the needs of the service users with the needs of the families, in addition to having the skills to involve them. Education, specifically about medications and medication management, emerged throughout the transcripts from a few stakeholders. However, service users were keen to point out that families could sometimes be over reliant on biomedical approaches and needed to be reminded that medications were not 'magic bullets' and have limitations as is demonstrated in the following quotation from a service user:

> The default of families is "are you taking your medication?". Because they see that as a magic bullet to cure…..In the beginning, it was always this mantra for my family "are you taking your meds, are you taking your meds?". Which now I look back at the damage that long-term medication can cause. I think nurses, even undergrads, should read on the consequences of long-term medication.

Valuing the role of the family

The final theme concerns the attitudes and values perceived as necessary for mental health nurses to work with families. While many values were discussed, the overarching value that emerged was that mental health nurses needed to value the role of the family. In addition, they needed to value the work the family do in supporting and caring for a person with a mental health problem. Recognising the role of the family as important was seen as paramount to working effectively with the family in order to implement the skills discussed earlier. The participants suggested that achieving these values also required mental health nurses to be aware of their own values and to be aware of their own attitudes and beliefs about the family. This included their experiences within their own families and their previous encounters with families. While some of the participants talked about a certain level of distance needed to work with families, they also suggested that there should be closeness as well which was required for professional development and growth.

> When you try to help someone you should understand that you are both equal persons. You need to be able to be close, but also to take some distance, to see things in a perspective. All the time there is a need to ask from yourself how you can help the other, why do you do this work, how you support the other ones' dignity and strengths?

There was a sense that this was couched in the idea the mental health professionals often see the family as opponents and sometimes believed that the service users' mental distress emerged from conflict within the family. This was particularly evident in the discussions about expressed emotion. The participants suggested that these values needed to be challenged thorough education and positive role modelling. The belief about the importance of the family and their role was set against other more generic values associated with mental health nursing such as dignity, respect, equality, openness, honesty, optimism and humour as is evidenced in the following quotation.

> The main thing is the ethical understanding, the way to see other human being as a person with his or her environment, as a member of his/her family. And to respect the family. There are so many different kind of families, and we should encounter them with respect and dignity, understand their ways of doing and listen to them carefully.

Some of the participants spoke about the dominance of the biomedical model and that there was sometimes an overreliance on this approach generally. The stakeholders argued that the mental health nurse should move away from the medical model and engage in practice that is underpinned by more recovery-orientated approaches. In this sense values and attitudes associated with recovery were also essential to working with the family. Specifically, the participants talked about the role of mutual support and self-help and the role of the mental health nurse in encouraging and facilitating this. However, this could not be achieved without mental health nurses first acknowledging the importance of peer approaches and having a positive attitude towards them.

Knowledge, skills and attitudes across the life – span

The participants were also asked to speak to the knowledge, skills and attitudes within a life span framework. Much of the data related to adult mental health although there were some points that spoke specifically to children or older people. In terms of children and adolescents, the participants repeated their suggestions that mental health nurses required knowledge and skills to work with children affected by mental distress. Specifically, they also talked about recognising and responding to children and adolescents who were affected by parental mental distress and ensuring that their needs were met.

While there was recognition that bullying could occur at any point across the lifespan, the participants spoke about the effects of bullying on children and adolescent mental health, in particularly cyber bullying. This was described as one of the factors that negatively impacted on this group's mental health and it was perceived that mental health nurses needed knowledge and awareness in this area. In addition, prevention and recognition of child abuse was also perceived as important knowledge and skills. Furthermore, for adolescents specifically, self-harm and suicidal behaviour were seen as important issues as well.

Regarding older people, much of the knowledge skills and attitudes were described in the context of dementia and informal carers, the nature of informal care and the role of the mental health nurse in supporting families who were affected by dementia. As with the adult content many of the knowledge, skills and attitudes were of general relevance to older people. Knowledge and skills that were exclusive to older people were the recognition and prevention of elder abuse and managing loneliness, which was seen as an issue especially for older people. Although physical health problems were seen as issues that affect people across the lifespan, their prevalence among older people and the impact they have on mental health were especially recognised as important issues for mental health nurses.

Discussion

The aim of this study was to present the findings from a consultation with mental health stakeholders to establish their perceptions of the knowledge, skills and attitudes required to inform eLearning materials to help mental health nurses to work with families and carers. The findings, presented here across three themes, provide a descriptive account of the important issues that mental health nurses need to be aware of when working with families and carers. On one level, the scope of the content described by the participants illuminates their depth of understanding of the issues and concerns of the families and carers affected by mental distress. On another level, they expose the breadth of knowledge, skills and attitudes that are required to work with families and the complexity of preparing mental health nurses to work in this

area. This suggests that programmes preparing mental health nurses for practice need to include specific theoretical education including opportunities for clinical experiences to work with families under supervision from experienced practitioners. This poses challenges for both undergraduate and postgraduate curricula. While our exploratory work sought to inform post registration or postgraduate education for mental health nurses, it is apparent from the findings presented here that the knowledge, skills and attitudes required to work with families need to be initiated at undergraduate level and built upon thereafter.

Mental health nursing has consistently argued that its philosophical standpoint emerges from an interpersonal framework that places unique emphasis on the relationship between the nurse and the service user. This has meant that a tension has emerged with the family and other carers which mental health nurses have found difficult to resolve. This was apparent in the findings presented here where the participants argued that nurses need to recognize and value the role of the family. This is consistent with other work in the area, such as REFOCUS/CPsychl (2013) who argue that the role of the family must be made explicit and that mental health professionals need to clearly understand the impact of mental distress on the family. Increasing awareness of the family and improving attitudes is also made difficult when historical negative attitudes towards the family may not have shifted within organizations (Standbridge & Burbach, 2007; Eassom et al., 2014). Furthermore, theories that have sought to explain mental distress, such as the schizophrenogenic mother (Seeman, 2009) or expressed emotion (Amaresha & Venkatasubramanian, 2012) may have inadvertently stigmatized family members and perpetuated stereotypes about families affected by mental distress. The importance of positive attitudes towards working with the family become obvious when we recognise that families search for meaning in a similar way as the people who experience the distress itself (Cairns, Reid, & Murray, 2015).

According to Stanbridge and Burbach (2007), high quality evidence supports the involvement of the family and carers and is associated with improved

outcomes for mental health service users. This underscores the importance of a positive relationship with families and the necessity of a coherent strategy for preparing mental health nurses for practice in this area. One way that this challenge might be addressed is by emphasising recovery orientated approaches as being important not just for service users but their families and carers as well. In this way recovery can become the underpinning philosophy for mental health nursing which can be used to interface with service users and their significant others. The central feature of recovery as espoused by Anthony (1993) is changing one's attitudes and beliefs about mental distress and creating new meaning and purpose in one's life. Using recovery orientated strategies will force mental health nurses to perceive service users as embedded within a social network that includes their families and other supports and will help them to look beyond the 'nurse-patient' dyad which can at times, stifle family involvement as suggested by Blomqvist and Ziegert (2011). This is not to undermine the relationship between mental health nurses and service users but rather to see that relationship as a segue to other important relationships that ultimately benefit the service users. In addition, the fundamental concepts associated with recovery such as hope, belief in the person and the multiplicity of perspectives beyond the biomedical model (Higgins & McBennett, 2007) will assist mental health nurses to foster a positive relationship with the key stakeholders in the service user's life.

Le Boutillier et al (2011) argues that for recovery orientated approaches to have traction there needs to be organisational commitment and a genuine desire to work in partnership with both service users and their families. While there is no doubt that that mental health nurses aspire to these values, there can be challenges to ensuring that families and carers are collaborators and partners. While recovery orientated practices are widely advocated throughout the literature, it is well recognised that there have been difficulties with translating them into mental health practice and that on-going education and training are required (Cleary & Dowling, 2009; Gaffey, Evans, & Walsh, 2016). There may be further difficulties encouraging their application to the service user's family as well. Emphasis on recovery orientated practices as being attitudinal, value based and requiring a change in mind set are difficult to

communicate but need to consistently be threaded through educational programmes to gain traction. In this study, there was some mention of recovery-orientated practices such as moving away from biomedical approaches and supporting or fostering hope. However, this mainly emerged from the UK and Irish partners where recovery has become more mainstream at least within mental health nursing educational programmes. Although recovery as a concept was not specifically mentioned in the other countries involved, some of the ideas and principles associated with it were alluded to. One explanation for this might be that 'recovery' as a term was not well used outside English speaking countries at the time. While recovery will certainly assist with the development of positive attitudes towards the family, specific knowledge and skills are also required as outlined in this paper.

Incorporating the vast array of knowledge and skills into both undergraduate and postgraduate education programmes is essential to ensure that emphasis is placed on the importance of the family and other carers. In addition, it will address some of the concerns of mental health nurses who feel their interventions are compromised by a lack of knowledge. Much of the knowledge content here is transferable and can be used in many contexts. While including vast amounts of knowledge in programmes may be unfeasible, educators need to ensure that knowledge and skills are transferable to a range of contexts including working with the family. During clinical practice, students need to be exposed to mental health nurses that are experienced with working with families and who are positive role models for the students. Family and systems theory were mentioned several times as background theories which could help mental health nurses understand the effects of mental distress on the family. However, mental health nurses need to remember that their strengths lie in the relationship that they can form with the service users and their families to provide support and education using the interpersonal skills that are fundamental to their role. This contrasts with a desire to move towards more formal therapy roles that could be perceived as a change in direction from traditional nursing interventions.

Limitations

Most of the data was translated to English for analysis and some of the meaning might have been lost during this process. As with any qualitative work, it is not possible to generalise the findings. The consultations took place in five European countries; therefore, it could be argued that the sample size was relatively small given the breadth of the countries involved.

Conclusion

The findings from this study underscore the complexity of the knowledge, skills and attitudes required by mental health nurses to work with families who are affected by mental health problems. In addition, it emphasizes the need for mental health nurses not only to be exposed to this knowledge during undergraduate and postgraduate education programmes but also that they are exposed to positive role models within clinical practice experiences. The findings from this study reveal that all the stakeholders involved have a comprehensive understanding of the needs of families and caregivers and that there is consensus between them about what knowledge, skills and attitudes are required. The eLearning materials designed following this consultation will assist mental health nurses and other professionals to review information relevant to this area that has been designed at Masters' level [www.eMenthe.eu].

References

Ali, L., Ahlström, B. H., Krevers, B., & Skärsäter, I. (2012). Daily life for young adults who care for a person with mental illness: a qualitative study. *Journal of Psychiatric and Mental Health Nursing*, *19*(7), 610-617.

Allerby, K., Sameby, B., Brain, C., Joas, E., Quinlan, P., Sjöström, N., ... & Waern, M. (2015). Stigma and burden among relatives of persons with schizophrenia: Results from the Swedish COAST study. *Psychiatric Services*, *66*(10), 1020-1026.

Amaresha, A. C., & Venkatasubramanian, G. (2012). Expressed emotion in schizophrenia: an overview. *Indian Journal of Psychological Medicine*, *34*(1), 12. -20.

Angermeyer, M.C., Schulze, B. & Dietrich, S. (2003). Courtesy stigma. *Social Psychiatry and Psychiatric Epidemiology*, 38(10), 593-602.

Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial rehabilitation journal*, *16*(4), 11.

Askey, R., Gamble, C., & Gray, R. (2007). Family work in first-onset psychosis a literature review. *Journal of Psychiatric and Mental Health Nursing,* 14(4), 356–365.

Awad, A.G., & Voruganti, L.N. (2008). The burden of schizophrenia on caregivers. *Pharmacoeconomics, 26*(2), 149-162.

Baronet, A. M. (1999). Factors associated with caregiver burden in mental illness: a critical review of the research literature. *Clinical Psychology Review*, *19*(7), 819-841.

Blomqvist, M., & Ziegert, K. (2011). 'Family in the waiting room': A Swedish study of nurses' conceptions of family participation in acute psychiatric inpatient settings. *International Journal of Mental Health Nursing*, *20*(3), 185-194.

Cairns, V. A., Reid, G. S., & Murray, C. (2015). Family members' experience of seeking help for first- episode psychosis on behalf of a loved one: a meta- synthesis of qualitative research. *Early Intervention in Psychiatry*, *9*(3), 185-199.

Cleary, A. & Dowling, M. (2009). Knowledge and attitudes of mental health professionals in Ireland to the concept of recovery in mental health: a questionnaire survey. *Journal of Psychiatric and Mental Health Nursing*, *16*(6), 539-545.

Corrigan, P. W., & Miller, F. E. (2004). Shame, blame, and contamination: A review of the impact of mental illness stigma on family members. *Journal of Mental Health*, *13*(6), 537-548.

Cree, L., Brooks, H. L., Berzins, K., Fraser, C., Lovell, K., & Bee, P. (2015). Carers' experiences of involvement in care planning: a qualitative exploration of the facilitators and barriers to engagement with mental health services. *BMC psychiatry*, 15(1), 208.

Eassom, E., Giacco, D., Dirik, A., & Priebe, S. (2014). Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors. *BMJ open*, *4*(10), e006108.

Expert Group on Mental Health Policy (2006) A Vision for Change: Report of the Expert Group on Mental Health Policy. Dublin: Department of Health.

Gaffey, K., Evans, D.S. & Walsh, F. (2016). Knowledge and attitudes of Irish Mental Health Professionals to the concept of recovery from mental illness–five years later. *Journal of Psychiatric and Mental Health Nursing*, *23*(6-7), 387-398.

Goodwin, V., & Happell, B. (2007). Psychiatric nurses' attitudes toward consumer and carer participation in care: Part 1—exploring the issues. *Policy, Politics, & Nursing Practice*, *8*(4), 276-284.

Goodwin, V., & Happell, B. (2008). Psychiatric nurses' attitudes toward consumer and carer participation in care: part 2—barriers to participation. *Policy, Politics, & Nursing Practice*, *9*(4), 249-256.

Higgins, A., & Mcbennett, P. D. (2007). The petals of recovery in a mental health context. *British Journal of Nursing*, *16*(14), 852-857.

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative health research*, *15*(9), 1277-1288.

Le Boutillier, C., Leamy, M., Bird, V. J., Davidson, L., Williams, J., & Slade, M. (2011). What does recovery mean in practice? A qualitative analysis of international recovery-oriented practice guidance. *Psychiatric services*, *62*(12), 1470-1476.

Loukissa, D.A. (1995). Family burden in chronic mental illness: a review of research studies. *Journal of Advanced Nursing, 21***(**2), 248-255.

Maurin, J. T., & Boyd, C. B. (1990). Burden of mental illness on the family: A critical review. *Archives of Psychiatric Nursing*, *4*(2), 99-107.

McAndrew, S., Warne, T., Fallon, D., & Moran, P. (2012). Young, gifted, and caring: A project narrative of young carers, their mental health, and getting them involved in education, research and practice. *International Journal of Mental Health Nursing*, *21*(1), 12-19.

O'Brien L., Brady P., Anand M. *et al.* (2011). Children of parents with a mental illness visiting psychiatric facilities: Perceptions of staff. *International Journal of Mental Health Nursing* ***20*****,** 358–363.

REFOCUS/CPsychl. (2013) *Who Cares? Listening to the Needs and Experiences of Carers of People with Mental Illness*. Dublin: Royal College of Psyciatrists.

Rowe, J. (2010). Information disclosure to family caregivers: Applying Thiroux's framework. *Nursing ethics*, *17*(4), 435-444.

Saunders, J.C. (2003). Families living with severe mental illness: A literature review. *Issues in Mental Health Nursing, 24***(**2), 175-198.

Schmid, R., Schielein, T., Binder, H., Hajak, G., & Spiessl, H. (2009). The forgotten caregivers: Siblings of schizophrenic patients. *International Journal of Psychiatry in Clinical Practice*, *13*(4), 326-337.

Schulze, B., & Rössler, W. (2005). Caregiver burden in mental illness: review of measurement, findings and interventions in 2004–2005. *Current Opinion in Psychiatry, 18****(***6), 684-691.

Seeman, M. V. (2009). The changing role of mother of the mentally ill: from schizophrenogenic mother to multigenerational caregiver. *Psychiatry: Interpersonal and Biological Processes*, *72*(3), 284-294.

Seikkula, J., & Olson, M.E. (2003). The Open Dialogue Approach to Acute Psychosis: Its Poetics and Micropolitics. *Family Process,* 42(3), 403- 418.

Seikkula, J., Alakare, B., & Aaltonen, J. (2011). The comprehensive open-dialogue approach in Western Lapland: II Long-term stability of acute psychosis outcomes in advanced community care. *Psychosis,* 3(3), 192-204.

Small, N., Harrison, J., & Newell, R. (2010). Carer burden in schizophrenia: considerations for nursing practice. *Mental Health Practice,* 14(4), 22-25.

Stanbridge, R., & Burbach, F. (2007). Developing family- inclusive mainstream mental health services. *Journal of Family Therapy*, *29*(1), 21-43.

Standbridge, R., and Burbach, F. (2007) Developing family inclusive mainstream mental health services, Journal of Family Therapy 29, 21-43.

Tranvag, O., & Kristoffersen, K. (2008). Experience of being the spouse/cohabitant of a person with bipolar affective disorder: A cumulative Process over time. *Scandinavian Journal of Caring Science,* 22 (1)**,** 5 – 18.

Tweedell, D., Forchuk, C., Jewell, J., & Steinnagel, L. (2004). Families' experience during recovery or nonrecovery from psychosis. *Archives of Psychiatric Nursing*, *18*(1), 17-25.

Vermeulen, B., Lauwers, H., Spruytte, N., Van Audenhove, C., Magro, C, Saunders, J., & Jones, K. (2015). Experiences of family caregivers for persons with severe mental illness: an international exploration. Leuven: LUCAS KU Leuven/EUFAMI. Available at: http://www.caringformentalhealth.org/c4c_reports/c4c_global.pdf. Accessed: 7th April 2017.

Wade, J. (2006). 'Crying alone with my child': Parenting a school age child diagnosed with bipolar disorder. *Issues in Mental Health Nursing,* 27(8)**,** 885 – 903.

Wilson, R.L., Cruickshank, M., & Lea L. (2012). Experiences of families who help young rural men with emergent mental health problems in a rural community in New South Wales. *Contemporary Nurse,* 42(2), 167 -177.

Table 1: Key Stakeholders across each University site.

University and Country	Stakeholders		
	MSc Mental Health Students	Senior Nurse Clinicians and Managers	Service users & families and carer organisations
Tampere University of Applied Sciences, Finland	7	13	2
Turku University of Applied Sciences, Finland.	5	7	2
Trinity College Dublin, Ireland.	4	4	2
Utrecht University of Applied Sciences, The Netherlands.	10	8	6
Halmstad University, Sweden.	7	11	10
University of Nottingham, United Kingdom.	4	6	1
Total	**37**	**49**	**23**