



A conceptual review of family involvement in acute mental health treatment: Methodology and personal reflections

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Abstract

This paper describes a process developed in order to work collaboratively on a conceptual review of some of the family involvement models that are used in acute mental health treatment. The members of the review team consisted of clinicians, academics and people with lived experience of mental illness and mental health services. This combination of backgrounds had the potential to present many challenges to the dynamics of the group. There were varying levels of research knowledge and experience within the group, as well as a lack of literature describing how to actualize their potential to best effect. Financial resources were minimal, which meant that the number of meetings had to be limited. Most importantly, however, there was the strong potential for a power imbalance within the group during the review process. Senior academics and clinicians were being expected to help to create a research environment in which the patient voice carried as much weight as theirs. In this paper, we discuss how we overcame these challenges and ended up with a process that was coherent, equitable and enjoyable.

Keywords: mental health; methodology; conceptual reviews; co-production; reflection

Key messages

- Co-researchers can have a profound influence on the research process and findings by participating in key stages that shape the analysis, without necessarily participating in all stages of a study.
- Complexity in research is not a reason to exclude co-researchers, but a reason to draw on them to gain a deeper understanding of the issues being examined.
- It is important to allow for flexibility and uncertainty in the research process, as this can enable the group to develop their own creative processes as concepts are reviewed, analysed and debated.

Background

In this article, we discuss our process of working together as a multidisciplinary team on a conceptual review of family involvement models (Dirik *et al.*, 2017), and our reflections throughout the process.

Many interventions or models exist to enable the involvement of family and friends (often called 'carers' or 'caregivers') in the care of patients with mental health problems. (We use the term 'patient' due to the nature of the setting, usually a psychiatric hospital. However, we recognize that any term used to describe a person accessing mental health services can be contentious, and that there is no single, preferred designation. We use the term 'family' broadly, to refer to any supportive individuals in a patient's life, not limited to relatives.) Evidence suggests that family involvement can result in many positive outcomes for patients, including reducing relapses (Pharoah *et al.*, 2010). Existing reviews in the field usually focus on how well a particular family involvement model works for a particular mental health condition, such as examining the effect of providing family intervention in early psychosis (Bird *et al.*, 2010). Many reviews also describe problems with implementing family involvement models in mental health services, particularly in the hospital/acute setting (for example, Bucci *et al.*, 2016; Eassom *et al.*, 2014).

We studied this issue from a different perspective by revisiting the fundamentals of the area and exploring what the term 'family involvement' means, particularly in the context of acute care. The aims of the review were to identify: (1) which family involvement models are used in acute mental health settings; (2) why they are used (their theoretical background); (3) how they are used (the components of the models); and (4) how they might be experienced by patients and families.

Conceptual reviews can be used in place of systematic reviews to explore concepts that are not clearly defined, such as 'psychiatric institutionalization' (Chow and Priebe, 2013) and 'good communication in psychiatry' (Priebe *et al.*, 2011). While they may contain elements of systematic review and narrative synthesis methods, they are more flexible in nature (Lilford *et al.*, 2001). As there was no evidence of lived experience representation in a conceptual review process, there were limited existing guidelines on which to draw. The following describes one way of approaching this kind of research process, while working to uphold the principles of inclusiveness and collaborative working.

Methodology, context and challenges

Conceptual reviews are subjective in nature, and are usually conducted with the support of a multidisciplinary group to reduce bias in the process (Lilford *et al.*, 2001). One or two lead researchers do the 'background work', which includes a literature review, data extraction, planning the group meetings and managing the thematic analysis process. The wider review team meets regularly to explore the emerging concepts in depth, and advises on the direction and content of the analysis. Traditionally, these review teams have only involved clinicians and academics. For example, previous conceptual reviews by Bonavigo and colleagues (2016) and Sandhu and colleagues (2015) have sought to understand the meaning of concepts such as 'dependency' and 'reciprocity' in mental health services and care. They have done so by using literature written from the perspective of the academic or clinician for the most part. This literature has been reviewed and conceptualized further by other academics and clinicians. The service user voice is either inferred or prescribed in their absence from these processes.

Similarly, the field of family involvement research is rich and varied, but is characterized by an absence of patient perspectives (Cohen *et al.*, 2013).

Another potential challenge was the context being explored. Acute psychiatric treatment is a sphere where power relations between clinicians and patients can be unbalanced, and mental health crises are one of the few medical situations where staff can routinely treat adult patients against their will. This can include forced medication or other practices, such as physical restraint and seclusion (Kaltiala-Heino *et al.*, 2000). Historically, conflicting and sometimes controversial views about the nature of psychiatry have led to many people becoming strongly opposed to the use of medical interventions for the treatment of psychiatric problems (Cooper, 2013). However, psychopharmacology remains a central mode of treatment for severe mental distress. Our topic area, therefore, was a contentious one, with the possibility that the group members might have very different, and even opposing, views about the nature of psychiatry.

In addition, due to limited financial resources, the review was conducted in a non-neutral space: an academic research centre located within a mental health hospital. The lead author was a mental health researcher and other members of the review team included two academic psychiatrists, a research psychologist and a senior nurse. Overall, the combination of the above factors meant the potential for imbalance within and between the members of the review team remained strong. Thus, it was extremely important to negotiate and mediate within our discussions, while remaining collaborative in our exploration of the selected texts.

Overall, there were some key challenges (summarized in Table 1) that made planning this process particularly complex. In the following section, we explain how they were addressed.

Table 1: Key challenges and worked solutions

Task	Challenges	Worked solutions
1. Setting up the team	Involving people with lived experience had not been done with this method before, so there were no immediate sources of guidance to draw upon.	Working with existing groups to develop ideas, a job description and application process.
2. Training	In order to contribute fully to the review process, all members of the review team would need to have sufficient understanding of thematic analysis and the research process.	Deciding on essential criteria in the job description. Setting up individual training and homework tasks.
3. Task allocation	The review was complex, with a broad search strategy (including a systematic search) involving several stages of narrative synthesis and thematic analysis.	Defining the primary aim of the collaboration, and then selecting relevant tasks.
4. Time allocation	There was limited modest funding, so it was necessary to find a way to maximize the contributions of all participants within a limited time frame.	Providing plain English summaries and sending email updates.
5. Forming a cohesive group	There was strong potential for a power imbalance in the meetings.	Holding pre- and post-meetings separately with lived experience researchers.

Worked solutions

Setting up the team

At the initial stages, academic/clinician colleagues signed up to join the review team but there was no funding to recruit members with lived experience. Moreover, it was unclear how they could be involved without prior experience in a conceptual review process. To address this, an iterative process of applying for funding and developing the review methodology was started, making use of available expertise.

AD met with the Centre for Public Engagement at Queen Mary University of London. Here, she discussed initial ideas and the scope of the funding available. Academic colleagues at the Unit for Social and Community Psychiatry were consulted on the process of conceptual reviews, patient and public involvement, and the review protocol. The Carers Trust's Mental Health Development Group and SUGAR (the Service User and Carer Group Advising on Research) were also consulted on the protocol. Additionally, AD had extensive discussions with SUGAR members on the recruitment process for individuals with lived experience and how best to facilitate involvement with them. This was done by sharing early drafts of a job description, application form and protocol for discussion with the group.

These multiple consultations resulted in several major decisions about the structure of the meetings, the number of people to be recruited and the recruitment criteria. For example, it was noted that potential fluctuations in mental health and other life circumstances could mean that some might drop in and out of meetings. Therefore, recruiting three individuals with lived experience would mean there would most likely be at least two people at each meeting.

Training

The need for all people involved in the review to have a certain level of research knowledge was addressed in two parts: at recruitment and during the study set-up.

For recruitment, essential criteria were set for each applicant to have at least some research experience, although a higher level (such as a formal qualification or publishing an article) was not necessary. The final job description was deliberately longer than is usual for a PPI (patient and public involvement) role. This was because anyone participating meaningfully in this process would need at least that level of understanding, as well as the ability to read two or three full pages of text. In contrast, the application form itself was kept very short, as writing skills were not essential to the role. Instead, all applicants were interviewed, either face-to-face or over the phone. Several people enquired about the role; 13 applied and were interviewed. After rating each candidate against the inclusion criteria, 3 people (KB, GB and SC) were recruited.

Before the review meetings started, AD had one-to-one meetings with KB, GB and SC to go through the principal features of systematic reviews, conceptual reviews and how to conduct a thematic analysis. Each person was given a thematic analysis exercise to practise at home beforehand. Before the first main review meeting, there was an opportunity to discuss any difficulties so far with thematic analysis, so that each person felt prepared for the upcoming tasks.

Task allocation: Managing the complexity of the review

During initial planning, AD listed the various stages of work needed for the review, before deciding which parts would benefit most from the perspective of people with lived experience. Several potential stages were identified, including: (1) conducting

the systematic search process for articles; (2) identifying theoretical references; (3) identifying the components of the models; and (4) exploring the role of patients and families in the delivery of the models.

When considering why and how to work with people with lived experience, the guiding principle was that people with personal experience could contribute depth to the analysis through their experiential knowledge. The tasks that would benefit most from such knowledge were identified as stages 3 (analysis of components) and 4 (analysis of the role of patients and families). If, instead, all team members carried out all tasks, the outcome of stages 1 (systematic search) and 2 (theory mapping) of the review would not greatly differ because of the involvement of people with lived experience. Arguably, this would not have been the best use of the team's limited time to work together:

- (1) **Systematic search:** In line with good practice, the inclusion criteria for the review materials had already been strictly defined beforehand, through consultation with academic colleagues, members of the Carers Trust and SUGAR. Therefore, within the scope of this project, involving the wider review team in the systematic search process seemed a poor use of their limited time.
- (2) **Theoretical references:** Similarly, part of the review required investigation of the theoretical references of the various models. This involved finding current and old intervention manuals and reading widely around the topic area to identify the original theories from which the models developed. While time-consuming, it did not need in-depth analysis. Considering the principles of co-production, involving individuals at this level risked tokenism, as their input would not have changed the outcomes of this descriptive process.
- (3) **Components** and (4) **the role of patients and families:** The stages of the narrative that would most benefit from personal experience were identified as: (3) understanding how the models were carried out, and (4) how this might relate to the role of patients and carers in the delivery of the models. For example, the review meetings were used to talk in depth about what it might mean to be a patient or family member on the receiving end of an intervention. Patients and family members with direct experience of acute mental health settings would, by definition, be able to give far richer perspectives on the family involvement models being discussed.

Time allocation

As the funding only allowed five two-hour meetings plus one hour of homework per meeting for each person, an additional challenge was to make the most of the limited time the team would have to work together. Therefore, sources were selected that covered the breadth of the reviewed literature.

AD undertook to identify the theories that influenced the development of the models. One family involvement model was chosen from within each theory for the whole review team to discuss in greater depth. This meant that there was coverage across the breadth of the theories being examined in the review. Before each meeting, AD would convert the key papers for the chosen family involvement model into a plain English summary. This was then shared with the whole review team, together with the original texts. The review team read through the summaries (with the option of also reading the full texts) and analysed the themes using the research questions (see Figure 1). AD also provided regular email updates as a strategy for maintaining a sense of continuity between the review meetings.

Figure 1: The meeting cycle

Forming a cohesive group

During the initial planning stage, AD had discussed with SUGAR strategies for reducing the potential for power imbalances within the meetings. One suggestion was to hold separate pre- and post-meetings with the lived experience researchers, giving them the space to talk outside the wider review team. A structure was set up whereby before the hour-long main review meeting, there was a 30-minute pre-meeting in which AD met with lived experience researchers KB, GB and SC. This was an opportunity to discuss the homework task in a smaller meeting and less intimidating forum.

The wider review team would then join the room, and the topics were discussed for a further hour. AD mainly took a facilitator role, asking questions and taking notes while the group shared their thoughts and developed their ideas about emerging themes. The wider review team members then left, and AD asked KB, GB and SC if they had any further comments or reflections to make about the meeting. This provided an opportunity to share suggestions for improvements for the next meeting.

Over time, the need for full-length pre- and post-meetings reduced, as the group became more cohesive and lived experience members were comfortable in sharing their views in the main meeting. Additionally, the structure of the homework tasks

changed, as patient and carer group members became more confident about their ability to analyse larger amounts of material, and in sharing their detailed notes within the larger group. This process happened organically, as the need for structure reduced and each person's understanding of the topic increased. Having this cohesive group greatly aided the iterative nature of the analysis, as ideas could be discussed across several meetings and integrated with AD's work outside the meetings. This process continued until joint agreement was reached about the themes, and was ultimately finalized at the last review meeting.

Conclusion

This was an experimental process that worked well due to early planning and consultation with others, and methodological flexibility. The involvement of individuals with lived experience provided new insights that were not previously considered by the academic and clinician members. The findings are fully discussed in our published article (Dirik *et al.*, 2017).

Below, we share our reflections on the process, how it impacted us personally and what could be improved. They are shared in their entirety to demonstrate the range of opinions and motivations. However, we would summarize the key helpful aspects as follows:

- our existing awareness of the potential pitfalls of poor collaboration, and our drive to avoid this
- all members contributing to an atmosphere where disagreement was acceptable, debate was welcomed and decisions could be made iteratively over the course of several discussions
- the value of background preparation, appropriate materials and making the most of existing expertise.

We would like to encourage other academics to adapt research methods that have traditionally been considered to be too complicated for wider involvement. This process was not only enjoyable but also highly valuable for gaining a deeper understanding of the issues being examined.

Reflections

Aysegul Dirik (lead researcher)

'Before this project started, I felt pressure to find a method of involvement that would be meaningful for all involved while actually contributing to the quality of the work being carried out. In part, what made the process work well was the initial preparation, including consulting several groups and organizations, and holding separate training sessions with each lived experience researcher.

'I was aware of possible criticism for being strict with the recruitment criteria, as this excluded some people from the process. However, having conducted public engagement in a previous job role, I was well aware of the downsides of recruiting individuals who did not have the experience and/or support to carry out the required work. This risked a tokenistic approach, whereby some members of the team would feel less able to contribute to group discussions and would potentially leave each meeting feeling excluded. To counterbalance this and widen the contribution, I consulted existing service user and carer groups to discuss the emerging themes. This

was enormously helpful for validating our findings and gave me the confidence that we were on the right track.'

Katherine Barrett (lived experience researcher)

'My involvement in this review included me taking part in several meetings comprised of service users and professionals. I liked the way these meetings were managed, as your views were listened to and I felt valued in what I said. Ayse, the lead researcher, wrote the notes up for us to share after each meeting, which was very helpful.

'I feel being involved in this review gave me new knowledge and understanding of family involvement. I learnt a lot by listening to other members of the team, and felt involved and encouraged to give my views. It worked well to involve the professionals and the service users in meetings rather than having two separate groups: one for service users and one for professionals.

'Each time we met we discussed a different intervention. Open Dialogue interested me because it puts the service user in the centre of their own individual world. By the time we had finished the meeting about Open Dialogue, I had a clear understanding of what it entailed and how it operated. It was great to work with such a knowledgeable group. Even though there was limited time (two hours), we covered a lot, and we could contact Ayse with more discussion on the telephone or via email. Each monthly meeting followed the same format with a different topic.

'I think the process of being involved in this review impacted on me by giving me more confidence to speak up. Sometimes service user involvement in research can be a bit tokenistic, but this experience was not at all like that. We were involved from the beginning as a whole group. Other researchers can learn from this.'

Gerry Bennison (lived experience researcher)

'The process was one founded on egalitarianism. Sometimes involvement does not automatically lead to engagement and change. But to be able to see the links and themes that underpin theory, and explore these in a human way, is when the value of PPI in research becomes very tangible and clear. This, for me, was the importance of being involved, that we provided an earnest lens on the concepts involved and their social impact, while retaining the "critical friend" complexity. We were valued for the whole of our experiences, not just for a composite part of the life course, and that's what made it work and feel meaningful. It is important to reflect on what it means to co-produce, that it is not competition to hold power and to match this as continuous challenge or shared role. It is the promotion of acceptance and value in the skills and abilities of all. It could be also argued that trust plays a key role where such tentative steps are required to ensure people are supported ... but also free to express and offer critical narrative. This was what the process brought ... a trust and earnest communication of critical perspectives and discourse without the hidden veil of unchecked power ... a freedom.'

Sue Collinson (lived experience researcher)

'I remember wanting very much to become a participant in this study, because I was intrigued by AD's concept of collaborating with people from different backgrounds, and with different experiences and views on the very nature of mental health (was it a social construct, a biological dysfunction or a massive enterprise to control people who somehow didn't conform to societal norms, and who saw themselves as "survivors"?), and I felt strongly that I wanted my voice in the mix. AD was an extremely good

facilitator, and helped us to be well-prepared for all of the meetings. Every member of the group was respectful of the opinions of others, despite the different perspectives around the table, and there was a complete absence of rank pulling by any of the professionals. I suppose the one missing aspect of the process for me was any sense that there would be some form of support for patients if their memories became in any sense distressing or overwhelming, but I missed the first meeting so that might well have been discussed then. I found being part of this innovative way of working to be rewarding and fascinating. I learnt a lot, felt able to share my experiences within the group, and would very much like to be involved in studies run along similar lines.'

Sima Sandhu (research psychologist)

'PPI in research can often feel like a wasted opportunity because involvement and engagement can take many forms, but not all forms are equal in the level of engagement. I think every member of the group was aware of the tokenism that can occur in research, including me, and we were all motivated to avoid this. The review process aided this immensely. The setting up and running of the review group avoided the traditional knowledge hierarchy, i.e. empirical knowledge is more objective or has more value than experiential knowledge for influencing policy and practice. I felt humbled by the limits of my practical knowledge, and valued the vast amount I learnt from listening to others in meetings and reflecting on the content afterwards. The review processes bred enthusiasm. This has been one of the most engaging pieces of research I have worked on. We often talk about ecological validity in research. I felt the structure of this review addressed this in a frank way through the extended discussions of various conceptualizations bounced off actual experience.'

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Notes on the contributors

Aysegul Dirik is an NIHR doctoral research fellow researching the following question: 'The involvement of family and friends in inpatient mental health care: What do patients want?'

Katherine Barrett is a service user researcher, with links to SURF (the North London Service User Research Forum).

Gerry Bennison is a user researcher, with wider links to Health and Social Care PPI.

Sue Collinson worked as a lecturer in medical education at a London medical school, until she became mentally unwell. After many periods of being an inpatient, and

receiving ECT, she is now stable on medication, and works in the NHS, case managing patients with complex physical and psychological problems.

Sima Sandhu is a postdoctoral research psychologist in the public sector.

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