

Title:

Involving People who Self-Harm in Research Design

Involving People who Self-Harm in Research Design

Type:

Brief Report

Care setting/Population:

People who have self-harmed and are in a general hospital.

Author:

1. Sandra Walker (Corresponding Author) (BSc(Hons), PCAP, RMN)
Lecturer, Mental Health
Southampton University
Faculty of Health Sciences
University Road
Southampton
Hants
UK
SO17 1BJ
Tel: 02380597897
Scw1y10@soton.ac.uk

Involving People who Self-Harm in Research Design

Abstract

Background (背景) and **Purpose** (目的)

5 In the UK, the expectation is that service users be involved in mental health research. This report outlines the process involved in exploring with a group of service users a proposed research project being carried out as part of a doctoral pathway into the experiences people admitted with self-harm had of contact with mental health services whilst in a general hospital.

10 **Methods** (方法)

A consultation event was held where the researcher outlined the proposed format of the project, the expected aims and outcomes. The group were asked to consider validity of the question being asked and to consider questions they felt needed to be asked as part of the process.

15 **Results** (結果),

The research question was amended in light of the consultation and the research methodology was influenced by the process. Some interesting linguistic points were noted as part of the consultation which has not been previously expected.

Conclusions / Implications for Practice (結論/實務應用)

20 Although the process was time consuming in terms of set up, it was immeasurably valuable in adding real world value to the project and ensuring that the research outcomes would be more likely to be meaningful to both service users and professionals alike.

25

Keywords:

Service User

Self-Harm

30 Involvement

Engagement

Mental Health Research

35

Introduction

Service User (SU) involvement is increasingly recognised as being central to health and social care policy and practice (DoH, 2005), education (Speers & Lathlean, 2015) and research (Lieba, 2010). Wallcraft (2012) points out that historically, mental health research has mainly ignored the views of the recipients of care and that the SU's subjective experience is often transformed into some kind of quantitative measure of observed behaviour. This is supported by Speers & Lathlean (2015) who add that SUs have invaluable insights to offer into both the conditions they have and their experience of using services. Involve (2012) assert that SUs offer different perspectives and priorities which can enhance the validity of the research and that they are often empowered by taking part in the process. Beresford (2005) defines a SU as a person who is 'on the receiving end or eligible to receive health and social care services.' Leiba (2010) states that it is essential to involve SUs as early as possible in the design and planning of research as they can have a real impact on the direction of the research and ensure that it remains valid from a SU perspective. In view of this and the discussion above, as part of the research design, a SU consultation was carried out. It was ascertained, via an email to the head of the local regional ethics committee prior to this event, that ethical approval was not required to carry out this consultation.

Methods

The group was comprised of 8 current and ex SUs (2 male and 6 female) who had all had experience of self-harm and psychosocial assessment whilst in a general hospital. Volunteers for the consultation were recruited via the local SU Involvement Worker, via regular local SU meetings and via posters, email and word of mouth. The reason for the consultation was to do the following:

- Explore whether the research question was valid and worth asking
- Ascertain what questions they felt were important to ask the research participants

It was hoped that this consultation would ascertain if the group felt the research idea was
65 valid from their perspective. The research idea was presented to them via a short PowerPoint
presentation during which they were invited to interrupt and ask questions at any point. Tea
and coffee was provided and the atmosphere was informal throughout. The meeting took
place in a local community centre in a room regularly used for SU events, in this setting an
informal discussion regarding the research and their views took place. The group were also
70 provided with the opportunity to respond via suggestion slips and email in case they were
unhappy to speak in front of others. No one required this and in the event all were happy to
speak.

The short PowerPoint presentation shared the proposed research question; the study outline as
75 seen at this time; potential outcomes; requests being made of the volunteers and the
researcher contact details to enable further communication should it be required.

Results

Prior to the consultation the research question was as follows:

80

How do adult SUs, admitted following self-harm, and clinicians experience the psychosocial
assessment in a general hospital setting?

The term psychosocial assessment is used extensively throughout nursing and social sciences
85 literature and guidance without any clear definition (NICE, 2011, Hawton et al 2006), it

appears to be an umbrella term used to describe an information gathering exercise which may or may not have therapeutic intention. As part of this process the term was explored since the intention was to include it in the question schedule.

90 **‘What does psychosocial assessment mean to you?’**

One of the main findings of the consultation was that the term ‘psychosocial assessment’ meant nothing to the group and required explanation before any further conversation could usefully continue. On exploring this further, it emerged that the word ‘psychosocial’ was dismissed as meaningless. They had no preconceptions of what this was, therefore did not
95 have any strong feelings. They asked for an explanation of the term and in discussing this it became clear that the processes they had experienced that were labelled psychosocial were very different depending on where they had been seen.

The most surprising outcome of the consultation was discovering that the term ‘assessment’,
100 in contrast to the dismissal of the word psychosocial, had many different and complex meanings for the group. The general consensus was that the term ‘assessed’ meant being judged with regard to whether the person is ‘good enough’, ‘mad’ or ‘needing hospital’, and being ‘tested’. The word was universally disliked but no one could think of a better word to use. This group were of the general opinion that the assessment is primarily service driven
105 and has little to do with SU need.

Having to explain and clarify terms during the research interview could influence participant views and potentially weaken the SU perspective, so the term ‘Psychosocial Assessment’ was removed from the question and participant information paperwork.

110

It was considered by the group, and is supported by literature (Mackay & Barrowclough, 2005. McHale & Felton, 2010.), that the views of practitioners in this context had often been sought and therefore there was little reason to repeat this. The group could see no valid reason for inclusion of staff perspectives in this research but clearly stated that they felt that the views of SUs in crisis were vastly underrepresented. In light of this the question was changed to its final form:

How do people who have self-harmed, experience contact with mental health services in a general hospital?

120

‘What should I ask the research participants?’

The group were also asked to consider questions they thought it would be pertinent to ask of the research participants. During this discussion several points were raised, the importance of good communication and the relationship between practitioner and SU were discussed in some detail. The group felt it was essential that the practitioner endeavoured to see the situation from the SUs perspective and stated that the process of assessment was transactional. They described the experience of assessment as often invalidating, particularly if the assessor is unable to stop their own values impacting on the outcome of the assessment and they felt that it was important that questions were framed positively. They suggested the question ‘Would you seek help here again?’ the implication being that a positive experience would be most likely to generate an affirmative response, so this was added to the question schedule as a prompt to use if the participant was struggling to create narrative without prompting.

135 **Discussion**

From the discussions above it became clear that the group felt the need for the issue of SU perspective during assessment to be important. This position is echoed throughout policy literature nationally (DoH, 2001, 2005) in all aspects of mental health recovery, service delivery and research. At the stage of the consultation the research methodology had not been
140 decided, but this emphasis on the perspective and experience of the individual was instrumental in the decision to use Interpretative Phenomenological Analysis (IPA) as the framework for this project.

Reid et al (2005) state that one of the key elements of IPA is that it is an inductive approach
145 that aims to discover and then explore the meanings assigned to experiences by the participant. This approach is now increasingly used in health and social sciences (Smith et al, 2009). Group members were clear that each person views the world from their own perspective and so judges others experiences and could come to conclusions that would be valid for them but not valid for others. This happens in a reciprocal way in the assessment
150 process however, the group pointed out that the clinician has a responsibility, in an assessment scenario, to 'enter into' the world of the SU so as to be able to assist them in finding solutions that would be valid for the SU. They described this as a highly validating experience. This description of the ideal assessment scenario is echoed by the principles of IPA and as such this methodological paradigm was adopted.

155

Summary

A summary of issues that demonstrate the impact of this consultation on this proposed research is as follows:

160

1. It influenced the methodology – Interpretive Phenomenological Analysis (IPA) – this was guided by the desire to see the situation from the SU perspective
2. The original intention to include clinician’s views was dropped
3. The question was reformulated
- 165 4. Suggested question to be included in the interview schedule when written

This report has described the process of a SU consultation carried out to inform the development of a research project exploring the experiences people who self-harm have of contact with mental health services within a general hospital. Whilst the exercise of setting up the consultation was time consuming, the overall effect was **considerable** and valuable both to the validity of the project and to the methodological decision making that form an essential part of the research process.

References

175 Beresford, P. (2005) *Theory and practice of user involvement in research*. In Lowes,L. & Hulatt, I. *Involving service users in Health and Social Care research*. Oxfordshire, Routeledge. ISBN 0415346479, 9780415346474

DOH (2001) *Shifting the Balance of Power within the NHS: Securing delivery*. In: DEPARTMENT OF HEALTH (ed.). London: The Stationary Office. doi/10.12968

DOH (2005) *Commissioning a Patient-led NHS* In: DEPARTMENT OF HEALTH (ed.). London: The Stationary Office.

http://webarchive.nationalarchives.gov.uk/20091106065608/http://dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4116716

- Hawton K, Rodham K and Evans E (2006) *By Their Own Young Hand: Deliberate self-harm and suicidal ideas in adolescents*. London: Jessica Kingsley. ISBN-13:978 84310 230 4
- 190 INVOLVE (2012) *Briefing notes for researchers: public involvement in NHS, public health and social care research*. Eastleigh. INVOLVE. ISBN 978-0-9559053-7-3
- Leiba, T. (2010) User Involvement in Research. In Weinstein, J. *Mental Health, Service User Involvement and Recovery*. London, Jessica Kingsley ISBN 1843106884, 9781843106883
- 195
- Mackay, N. Barrowclough, C. (2005) A&E staff's perception of DSH: Attributions, emotions and willingness to help. *British Journal of Clinical Psychology*. 44: 255-267 DOI: 10.1348/014466505X29620
- 200 Mchale J and Felton A (2010) Self-Harm: what's the problem? A literature review of the factors affecting attitudes towards self-harm. *Journal of Psychiatric & Mental Health Nursing* 17: 732-740 DOI: 10.1111/j.1365-2850.2010.01600.x
- National Institute of Clinical Excellence (2011) *Self-harm in over 8s: long-term management*. London, NICE. <https://www.nice.org.uk/guidance/cg133>
- 205
- Reid, K., Flowers, P., and Larkin, M. (2005) Exploring lived experience. *Psychologist*, 18 (1). pp. 20-23. ISSN: 0952-8229

210 Smith, J. (2009) *Qualitative Psychology: A practical guide to research methods*. London,
Sage. ISBN 1446234991, 9781446234990

Speers J. Lathlean J. (2015) Service user involvement in giving mental health students
feedback on placement: A participatory action research study. *Nurse Education Today*. 35(9):
215 e84-e89. doi:10.1016/j.nedt.2015.07.004

Wallcraft, J. (2012) What has been learned from joint working between mental health
professionals, patients and users of psychiatric services, their families and friends? *Current
Opinion in Psychiatry*. 25(4): 317-321 doi: 10.1097/YCO.0b013e32835462d0

220