

Scottish Recovery Network

Researching recovery from mental health problems

SRN Discussion Paper Series: Paper 3

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About the SRN Discussion Papers Series

This is one of a series of discussion papers designed to help generate debate on how best to promote and support recovery from long-term mental health problems in Scotland. A number of source materials were used to inform its development and it is hoped that over time it will be developed and adapted in the light of learning and comments from people around Scotland who have an interest in promoting and supporting recovery from long-term mental health problems.

Contact the Scottish Recovery Network for more details on the series.

About the author

Kathryn Berzins is a Research Associate in the Public Health and Health Policy Section at the University of Glasgow. Her research interest is the experiences of people with mental health problems living in the community, in particular factors affecting quality of life. She is currently researching the role of social networks in the lives of people with mental health problems, in partnership with SAMH and NSF (Scotland).



Summary

This discussion paper examines the issues involved in researching recovery from mental illness in advance of the Scottish Recovery Network's research project on that theme. It discusses some of the strengths and weaknesses of different approaches to research and argues that qualitative methods are suitable for the generation of rich, narrative accounts of lived experiences that may aid the identification of factors promoting recovery. The importance of Scottish research is acknowledged and a summary of some of the ethical issues raised by qualitative research is given. It concludes that a qualitative research study of people's experiences in Scotland will establish an evidence base that can be used for service development and the generation of further research that will contribute to the understanding and promotion of recovery.

Introduction

'In moving beyond symptoms and deficits, it is vital that we start in a different place, i.e. with the voice of first-hand experience. We need to begin by listening to people who have mental health problems. We must gain insight into the possibilities of life with mental health problems.' (Repper and Perkins, 2003)

One of the aims of the Scottish Recovery Network is to explore the experiences of people who are recovered from or living well with mental health problems. The majority of people who experience mental ill health recover (Harding, 1994) but what does this process involve?

Recovery is a complex personal journey; no two experiences of either illness or recovery are identical although they may share common features. Approaches to understanding recovery are holistic; they do not focus solely on the traditional biomedical notion of the absence or reduction of symptoms, but attempt to understand people's experience in the broader context of their lives. People draw on both internal and external sources of support, developing their own inner resilience and ways of coping, whilst drawing on the support of family and friends, employment and a range of specialised and generic services.

Understanding the process of recovery can be as important as understanding the outcome, but how can we best go about doing this?

Research approaches

One of the most important decisions in research involves choosing a method that is capable of answering your particular set of research questions. Sometimes these questions are very simple, e.g. we might want to predict how people will vote in a forthcoming election by asking a single survey-type question with a restricted set of answers relating to relevant political parties. If we want to understand what other factors might influence voting choice, we would include further survey questions relating, for example, to people's gender, income or other background characteristics. These responses can be analysed statistically using computer software to show how these different factors relate to each other and to voting preference. This is a form of 'quantitative' ('number-based') research, which is often seen as rigorous, 'scientific', and consisting of reliable, 'hard facts'.

There are many research questions, however, that cannot be adequately answered using quantitative methods alone and a complex set of questions may require a different approach. A holistic understanding of a people's sets of experiences requires participants to feel free to talk in general terms on subjects that they themselves define as important and is unlikely to benefit from a survey containing a limited number of questions that force them into a narrow range of pre-defined responses. This is where the 'qualitative' approach to research becomes of use.

Instead of asking respondents survey-type questions, the researcher (often in the context of an informal interview) asks participants more general questions that are designed to encourage the free expression of thoughts, feelings and experiences. A qualitative interview can be more or less structured but generally the aim is to ensure



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that participants talk about specific topics whilst being free to 'tell their own story'. 'Good' interviewing may be seen, therefore, as a kind of 'guided conversation' that strikes a compromise between the research agenda of the interviewer and the right of the person being interviewed to speak about their experiences in their own way.

Research is sometimes thought to be either quantitative or qualitative but whilst the two sets of methods have different aims (the former, to produce 'general laws' that can be used for prediction, and the latter, to understand people's lived experiences), they are essentially complementary and are increasingly used as such. For example, quantitative (survey) methods might be used to demonstrate that a treatment has improved the health of a group of people whilst qualitative methods (interviews) might be used to give insights into how this happened. The research proposed by the Scottish Recovery Network would use both approaches in that it would collect personal information about the participants, including gender, age and other background characteristics, that would allow subdivisions and comparisons between groups, (e.g. the experiences of women compared to those of men), before going on to ask very open questions that encourage people to tell their stories.

Researching recovery

The active promotion of recovery with people with mental health problems is a relatively new concept and does not yet have an established research evidence base. Previous research in the area has been largely of a qualitative nature and these narrative accounts have informed the development of quantitative measurement scales that have assisted in the planning and monitoring of mental health support services (Ralph et al 2000; Ensfield et al, 1998).

Recovery refers to a complex set of processes and each story of recovery is unique to the individual. It is a truly subjective experience and it is important that researchers are receptive to this and do not hold assumptions about what recovery consists of. We cannot assume that what has been important to one person will be as important to another, indeed, it may not be important at all. Additionally, there may be common experiences that have helped many people or that have been of great importance to fewer people; some things may help during an earlier part of the process but not later.

A qualitative approach to researching recovery encourages people to tell their stories in as free a way as possible. It encourages participants to reflect on all areas of their lives during the recovery process and to think about what they have found both helpful and unhelpful, and to describe the reasons for this. When people give a narrative of their experiences they often use it as a basis for organising and reflecting on their experiences (Coleman and Smith, 1997; Coleman, 1999) and in this way, many research participants find the experience to be both positive and affirming, although they may be also be recounting painful and distressing experiences.

Participants are given the space and time to tell their story within a non-judgemental, safe environment, which may be a new and valued experience for them. They can also gain a sense of satisfaction through feeling that by telling their experiences they may help others in the future.



The importance of Scottish recovery research

To date, most of the research on recovery is based on the experiences of people with mental health problems in other countries, most prominently New Zealand and the United States. Whilst not invalid, these findings cannot be applied uncritically to the UK context due to the very different sets of support services and health policies employed here. The situation is further complicated by the fact that Scotland, has its own health and social care system (distinct from England & Wales) with the Scottish Executive determining health policy. Thus there is a clear and urgent need for uniquely Scottish research that is capable of informing national policy and practice.

The Scottish Recovery Network's project is an opportunity to lay the foundations of such an evidence base and in addition to generate detailed and rich accounts of people's lived experiences. The emerging themes will help identify areas that require more specific investigation which may influence further research.

Investigation of the recovery process does not explicitly focus on the role of mental health services but they will inevitably feature in many people's experience. Over the past decade there has been a shift in policy and mental health service provision to become more responsive to the view of the service users themselves. This is often done by agencies holding consultations with their service users or the wider mental health community. Due to the considerable costs of carrying out this type of research, the Scottish Recovery Network's research project will provide a resource that all services providers can use to examine how their particular service can develop a recovery focus.

Ethical considerations

Asking people to tell their recovery stories may involve describing very personal and painful experiences. Researchers are ethically bound to minimise the harm involved in participation and this involves thinking carefully about our methods. If we require people to fill in a postal survey of their experiences, we are not in a position to know if doing so has upset them or affected them adversely in other ways. If, however, we collect people's stories in an environment they are comfortable with and in the context of a supportive face-to-face interview, we are minimising this risk. The researcher can provide reassurance and answer any concerns the participant may have about the purpose of the research and what will happen to the information they provide. They can also provide information about sources of further support. However, it is important to be clear that the interview is not an overtly therapeutic process, and that the role of the researcher is essentially to gain information from a willing provider.

Finally, it is now becoming more common for participants to be paid for taking part in research, particularly where an interview can last several hours. This can be a contentious issue and needs careful consideration. The payment must not be at such a level that it could lead people to take part in something that they would not otherwise have volunteered for or that may be against their best interests. Additionally, if they are receiving means-tested benefits, it cannot be at such a level as to interfere with their payment. However, if these conditions are met and payment

is offered, it is generally welcomed by participants as an acknowledgement of the time they have given to share their experiences.

Conclusion

An exploration of recovery in Scotland of this nature will draw directly on the experiences of people who have been affected by mental health problems. Taking a qualitative approach to the exploration of personal narratives will allow greater understanding of the factors that have influenced the recovery process. It will ensure that the experiences of people living in Scotland are added to the growing United Kingdom and international evidence base. This evidence has the capacity to inform both service development and generate further research that will contribute to the understanding and promotion of recovery in Scotland.

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