Unintentional participant observation: a research method to inform peer support in mental health?

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Abstract

Purpose – The purpose of this paper is to validate peer support in mental health care.
Design/methodology/approach – Literature review and meta-analysis methodology are used.
Findings – The unintentional nature of peer support is a valid methodology for the understanding of mental health issues and mental health care.
Research limitations/implications – The limitation is that peer experience should be accepted as a valued method for research.
Practical implications – Professional domains may not keep a monopoly of research approaches in mental health.
Social implications – Peer support may mean more avenues for empowerment of mental health service users from peer role models who have unintentional acquaintance with mental health issues and care.
Originality/value – This research refers to ethnographic precedents to describe methodology relevant to twenty-first century peer support in mental health. It is original in valuing the unintentional participant observation acquired from experience of the mental health system.
Keywords Ethnography, Mental health, Peer support, Lived experience
Paper type Viewpoint

"With akathisia there is never any peace from this insistent urge to move, be it rock backwards and forwards in a chair, shuffle around the wards, kneel and huddle in a chair or go for a walk. It is like a tinnitus of the body; there is never a moment of inner silence" (Peter Chadwick, British Psychological Society, 2014, p. 96). What Peter is able to describe cannot be experienced vicariously. So-called objective methods like the Barnes Akathisia scale ignore the personal effect written in Peter's words, it is impossible to replicate the symptoms in Peter's piece or to understand the feelings except first hand. A caregiver or professional in mental health could not have written this authentic memorandum of lived experience.

This essay will seek to explore how issues such as Peter's can validate the place of peers in delivering mental health services. It will draw on the methodology of participant observation and ethnography to evidence the legitimacy of qualitative methods evolving from the narratives of mental health service users. I will seek to show how this can underpin the validity of peer workers in a clinical setting. That is to say that peer workers will have lived experience of mental health issues, and association with the mental health system of care. They will have acquired this status unintentionally.

An established methodology in social science, Ethnography or Participant Observation has roots in the work of Talcott Parsons, Malinowski and other researchers of developing societies. Participant observation was taken a big step forward with the work of Erving Goffman and Ken Kesey in the 1950s and 1960s when they embedded themselves in psychiatric institutions. Their first hand observation of the social networks within mental hospitals remains a benchmark in the twenty-first century.

But what of the experience of the patients themselves? Many modern services work to the recovery model, and there are a number of empowered individuals who can apply recovered values to what did not work and what does work. They have not made a deliberate choice to enter psychiatric institutions, yet are experts by experience with insight of recovery journeys.

Today such people can find themselves in employment as peer workers at every level from ward to board. This essay seeks to put into context the value coming from experience of the system and how the user voice can be enabled through peer support, an unplanned pathway but now integral in many UK services.

The ethical stance of the essay is to hear diverse voices as they lead to renewed sense of self, a new identity. It is not to apply standards or interests except those of the service user and to listen. There is recognition of the equality between service users. Each has her or his own personal history from their unsought journey through symptoms and the system. Each can validate unintentional participant observation.

Petra Boynton (2017) seeks to find a path for research beyond the traditional divide between quantitative and qualitative methodology, yet begins as do most discourses with reference to an ethical approach. She asks (p. 91) what a study means for stakeholder groups: researcher, participant and relevant others. So if we are looking at a research method that can inform peer support, legitimacy will interrogate those stakeholders. Clearly there is lack of distinction between researcher and participant – they are the same. The researcher is the participant in unintentional participant observation. The researcher can have an historical or temporal relationship with the study. That can be her or his point of view as a service user and as a peer worker. Only the researcher/participant can describe what it feels like to be a patient; to know the judgement, the alienation, the prejudice and the lack of fulfilment. Only the peer can empathise with fellows experiencing mental illness and the psychiatric system, as one who has been there. Insight is a precious commodity and its value is to the researcher/participant, and informs the processing of contacts in the mind of the unintentional ethnographer, those contacts with others.

So at the outset, the unintentional participant observer should ask herself or himself: why am I engaging in this activity? Who am I engaging with, and what is my relationship to others? Am I sure I am acting without untoward incentive or influence, and can my activity add to and assist the user voice to be heard? How do I deal with being paid to work as an ex-inmate in a clinical setting?

Since the implementation of the 1990 Community Care legislation, the health service has provided service user involvement, the recovery model, and peer support. Previously these were unavailable. So the NHS has created a pool of recovered patients, and is hence organising peer support. The NHS has brought about and funded this pool of peer workers. Is it therefore in the interests of peer applicants to disclose as much of their history as will get them onto the peer support payroll?

There are two potentially conflicting aspects of peer involvement: independence and remuneration. So if a part of peer support work is to advocate for the user voice to be heard without mitigation, what if the peer has split loyalties to the interests of her or his employer. The peer may need to keep her or his paid role, yet the employer may have demands affecting the independence of the peer's work.

Perhaps the two most influential writers in composing this essay are Erving Goffman and Ken Kesey. Both were active from the 1950s and 1960s onwards and made a trademark of participant observation. It is also handily useful that they wrote in the field of mental health.

Goffman represents the individual in a capacity as someone who may be simply present, or may be a co-participant. Goffman (1971) stresses the toxicity of the situation of the psychiatric patient, who pays a price of: "dislocation from civil life, alienation from loved ones who arranged the commitment. This has been not merely a bad deal; it has been a grotesque one" (p. 336). He writes of two or more persons who collude to manage an "excolluded" other. Non-participation has led to exclusion. What individuals are for Goffman, are relationships, organisations and communities. This is what he studies. Peer supporters, experts by experience, have unintentionally and perhaps unknowingly been in these situations, and as such have a knowledge on a par with Goffman's, and that reservoir is ready to be tapped.

Peer support specialists have an aspect into life in the psychiatric system which they can measure in terms of justice, critical analysis, social policy, social history, empowerment and transparency. Some are active in this sense while detained and possibly still deluded, and some have this insight in recovery. They share with Goffman, Kesey and others that they have first hand witness. The difference is that participant observers will have their observation with an element of vicariousness (they are not the first person) – unintentional participant observers will have full on lived experience. One has an observer point of view, for the other it is their life. Both seek to make sense of a life, to give a person's story in their own words and images.

In his introduction to *One Flew Over The Cuckoo's Nest*, a seminal work of its time by Ken Kesey, Faggen writes about the possible conflict of interest that might befall peer specialists. So by encouraging dialogue of a certain type, a false dialogue from service users, a coercive situation arises where the service user is open but only in the way that the system demands. The old mental hospitals at their best encouraged dialogue, but only to bring about discharge upon being judged as socially acceptable. The "model patient" conformity is not the same as genuine voice. Therefore, are peer support specialists just doing the dirty work for the system, and colluding to make service users uncolluding persons with a false representation? This is a highly relevant conversation.

For peer support specialists have indeed the potential to transform participant observation into unintentional ethnography. A unique aspect of peer support is the shared experience that is brought to the mental health environment. This can be a special opening into the service user perspective. The service user voice, her or his sense of self, can be enabled through the shared experience. A way to the authentic user voice is through the peer worker. From being disempowered during the two or three centuries of the asylum colonies, the person with mental health needs can be again accepted into society, through challenges to stereotyping and having the unadulterated version of their issues and life listened to.

Faggen points out that in the book by Kesey, terms such as "schizophrenic" demean the individual. The individual's unique characteristics are ignored, her or his humour, originality, even her or his visionary quality. This is clearly problematic to individuals with such characteristics, and of course to those from a culture where they are valued for such as visionary quality. Culture indeed includes Kesey's financing the adventure with the Merry Pranksters in the West Coast underground in the USA. The Pranksters were made famous in Tom Woolfe's "The Electric Kool-Aid Acid Test" and they embraced a new sub culture based around LSD and other drugs, in the first years of the 1960s.

Can peer support really delve into these questions?

So I turn now to Petra Boynton and her perspective on research methodology. Adventure, dynamic, empowering, applicable, knowledge, truth, informed imagination, sharing and emancipatory. These are words used by Boynton and her friends to sum up "research" (p. 1). She sees research as a journey for researcher and participant. Her aims are to empower participants and communities, to make use of researchers' experiences and stories, to cover issues not commonly covered. She criticises researchers in the main for being unrepresentative (It can be said of peers that they are indeed representative of their environment and community). Participants need to be involved in the design of research at all stages, to decide what methods are used in research (Peer workers are involved from the start with their experience). It is key for participants to have a voice in the way research is conducted. Researchers cannot think of all the questions that a participant will originate – hence a place for unintentional participant observation. Boynton writes that "[…] participant stories can be integral to educating others and raising awareness […]", and that innovation can include storytelling and cartoon.

To take two of the descriptor words Boynton mentions, sharing and empowerment, there is an explicit crossover with the Peer Support Charter from NSUN. For the Charter, a principle is empathy where there is sharing the feelings of another; another principle is commonality with shared beliefs; and a third is mutual benefit where there is sharing things and feelings. Another principle of the charter is equality where there is equal power – an implied requirement for empowerment. I propose that there is a link between the type of research ethos underpinning Boynton's work and the principles in the peer support charter. This link is for me a relevant statement of the value and purpose of unintentional participant observation.

How can this link in with Peter Chadwick's statement above about how it feels to suffer Akathisia? What it means is that an unintentional participant with lived experience such as Peter, will recognise the discomfort of others from her or his history. Even a participant observer, not necessarily a professional but professionals too, will have to be aware of the Barnes Akathisia scale to recognise Akathisia. If they have not been trained in Barnes Akathisia scale, the chances of them making a difference are lessened. A participant ethnographer will know to apply their experience in the gathering of data.

There is a myriad of circumstances where lived experience will enable the cutting edge of research. From resettlement in an out of area placement to the acquisition of multiple diagnoses in a journey around the system, from the numbing alienation of years disrupted by illness or in the system to escaping supervision to endure untreated psychosis, from being rejected by the health service and ending with a criminal record to becoming an addict in hopeless discharge surroundings, this will be some of the life experience that may guide a peer worker. This experience can be tapped for the intervention of unintentional participant observation.

So I wish to advocate for the validity of the peer worker with lived experience of mental illness, to be welcomed as a researcher both for her or his retrospective view, but also for her or his triangulation of the experience of suffering an illness and being in the mental health system. Kesey and Goffman led the way in giving insights into participant observation with their milieu being mental health. This led away from the purveyance of expertise by a medical and research elite. Goffman and Kesey humanised mental health. By embedding themselves with the objects of study, the patients, they gave them a voice and understood them as people, not the labels that accompanied them and blighted lives. They even began to describe cultural value in inpatients that was beyond Western norms. For these writers, to be a visionary no longer meant being categorised as insane, and to originate from a culture where shamanism was valued became acceptable to treat as a respectable attribute. This was the start of the recognition of today's protected characteristics in the UK.

So is there any precedent or existing body of work that can add the research function to the usefulness of the peer movement in its capacity of delivering services? Yes there certainly is. Peter Chadwick has explored this with "Schizophrenia, the positive perspective". Peter's lived experience has enabled him to document the psychotic episodes of others. This is how an existing link to a condition can enable the telling of narratives of others through an academic lens. But if we look further, there is a huge resource of service user narrative which can give a retrospective onto mental health. Peter Thompson's books of the 1970s, *Bound For Broadmoor* and *Back From Broadmoor* are autobiographical histories of mental illness detailing explicitly the harm, risk and jeopardy which Peter lived through. Peter gives his story in his own terms, not those that will appear on his medical record, such as diagnosis, prognosis, record of interventions, dealings with the home office and daily clinical records. These will have been the substance of discussions in medical teams during Peter's stay in high security. He touches on very little of this, and writes about his contacts with fellow inmates, staff, supporters on the outside, his writing, and how he is trying to prepare himself for freedom. Probably, reciprocity prevails and there will be very little of Peter's perception of those days, months and years. For a researcher this will be invaluable material. The volumes of service user narrative are now many and varied. Each is a record that will be similar to Peter Thompson's in that it gives a different version of who someone is, compared to official and medical records. It is the value of peer support that very few, if any, peer support specialists will have come through the route of clinical training. They will have been prepared through the user movement to value independence, hearing the user voice and empowerment. But they will not have undergone regular semesters of medical training duly examined and signed off.

There are also a number of compendiums of service user histories, including *Our Encounters with Madness* and *Mental Health Recovery Heroes Past and Present*. These have been arranged and edited by mental health professionals and give a version of the service self.

I maintain that every peer support worker will have within herself or himself such a retrospective history. Given the tools to research the current patient population, they will have the perspective of a participant ethnographer. However they will not be voluntary ethnographers, they will be unintentional participant observers.

With this kind of argument, you are either "on the bus" or "off the bus". There are those who do not value peer workers or see the point of peer support, within professions but also among service users. For the community of mental health service users actually or by aspiration involved in the planning and delivery of care, it is an integral part of their practice that they have a value to their peers, can facilitate patient outcomes, can advocate from experience, can act as role models and have actually shared that place where current service users are. On recovery journeys those with mental health issues have a unique perspective that can go alongside regular health workers' practice. They are unquestionably fitted to use their unintended experience to good, to conduct empowering research.

References

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