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Title: Researching service user views in forensic mental health: a literature review

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Abstract

There is increasing emphasis being placed on gaining users' views of health service provision. Forensic mental health services are provided within the context of twin challenges presented by those receiving services and societal responses. Service user views however can inform professional responses to their complex needs.
The aim of this review is to explore the methodological approaches used to access perspectives of users of forensic mental health services, to critique these approaches and explore the range of views of users of forensic mental health services. The primary method employed was a literature review of research papers explicitly accessing perspectives of those categorised as mentally disordered offenders or users of forensic services. The main findings were as follows;
Firstly, both the volume and breadth of studies exploring service users' views are limited and limiting. Secondly, studies demonstrate significant flaws in terms of the conduct, application and reporting of the research process. Thirdly, service users across studies indicate both positive and negative aspects of their experiences of caring and concern with restrictions on their liberty as inpatients and as community residents. Lastly, given the complexity of ethical issues with largely captive populations there is a striking absence of discussion on ethical problems in forensic mental health research.
The range of approaches to accessing service user perspectives in forensic mental health services requires expanding both methodologically and theoretically. The application of quality criteria should be more consistent and applied rigorously. A consequence of this is we still know relatively little of the experience and perspectives of people who use forensic mental health services and may judge available findings as unreliable.

Key words: Forensic mental health, service user views, literature review, research methods.

Introduction

Forensic mental health services in line with other health and social care providers are giving increased attention to the views of recipients of care (Faulkner and Morris 2003). There are a number of reasons for this for example, it may help to determine health needs and lead to improvements in quality of life and satisfaction with services (Sullivan 2003). Although service user involvement has been introduced ostensibly for political reasons it may improve quality of services despite being limited by organisational agendas (Rutter et al, 2004). Mentally disordered offenders are often treated differently from other groups and consequently they experience discrimination and social exclusion limiting opportunities for recovery and reintegration (Porporino and Motiuk 1995). With greater consumer input to health services a review of the literature in this field exploring the range of methods employed, the quality of this research and the views of service users is prescient.

Background

Internationally, the treatment of people with mental illness convicted of a criminal offence occurs in high secure health and/or correctional facilities, and in the community, (Skipworth and Humberstone 2002; Renzaglia et al, 2004; Muller-Isberner, 1996). In the UK it has been estimated that most (88%) forensic service users are male, predominantly single, between the ages of 21-30 years old with the majority of indictable offences involving violence against the person (Street 1998).

People with mental health problems can be seen to lack objectivity in determining the appropriateness and quality of care they receive (Lebow, 1982) leading to a reluctance to seek their views. Mental illness does not however preclude people from offering clear, valid and objective perspectives on the services they receive (Lidz et al, 1995; Hoge et al, 1998). Further it has been noted that people with psychiatric conditions are capable of comprehending and giving informed consent to participate in research (Carpenter et al, 2000; Pinals et al, 1998).

There is increasing research material in the general psychiatric literature of service users' experiences of care. This includes methods that encompass first person accounts (Leete 1989), narratives approaches (Barker, et al 2001; Olofsson and Jacobsson, 2001), symbolic interactionist approaches (Karp 1995), group interviews (Barham and Hayward 1995) and phenomenological accounts of recovery (Davidson 2003). These accounts illustrate the social hurdles people with mental health problems must overcome to effect recovery. Such hurdles include discrimination, difficulty in finding employment, public indifference, difficulties in establishing relationships and poor or inadequate housing (Kelly, 2005). In addition those with enduring mental health problems experience significant threats to their sense of self as well as their social identity (Estroff 1989). For mentally disordered offenders the added factor of criminal history may result in social exclusion, increased scrutiny by health, social and criminal justice services and experiences of discrimination (Teplin, 1984; Kelly, 2005).

Search Methods

This study reviewed empirically based peer-reviewed papers on service users' views of forensic mental health provision with the aim of;

1. establishing the range of methodological approaches to this topic

2. critiquing methodological approaches used to gain service user views

3. establishing the range of views from service users about services

Applied Social Sciences Index and Abstracts (ASSIA), Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed, Psych-Info, Sociological abstracts, and Social Service abstracts were searched for material published in English between 1990 and 2004. Search terms included combinations of the words "forensic" and "mentally disordered" with a range of terms used to describe recipients of services including service users, patients, consumers, survivors, and clients. Papers that did not directly refer to forensic mental health settings were excluded.

This process produced 21 research papers of service user views (16 UK papers, 2 US papers and 3 Canadian papers). A review paper on service user involvement published as a report for the UK Department of Health Forensic Mental Health Programme (Faulkner and Morris 2003) was used as background material. A research report for the UK Home Office that included service user views (Dell and Grounds 1995) and a user-led research report sponsored by a mental health charity (Rees and Water 2003) were also included in the review.

Criteria for judging quality of papers reviewed

Methodological rigour is a key issue in determining the quality of research. In quantitative research there is relative agreement about constructs such as validity, reliability and generalisability. Quantitative research offers high credibility and features on hierarchies of evidence that are valued by many practitioners (Geddes and Harrison 1997). Sufficiently powered samples, the use of randomisation in sample selection and comparison with a control group are important constituent elements of methods at the top of these hierarchies and assuming studies are conducted adequately they offer useful evidence (Kunz and Oxman 1998; Marks 2003).

Judging the quality of qualitative methodologies has exercised researchers for a number of years (Murphy et al, 1998; Elliot et al, 1999; Seale, 1999). Papers included in this review utilising qualitative methods have been judged in regard to the following principles.

The conduct and reporting of the research process is an important established feature of qualitative research (Spence et al, 2003) and studies must clearly detail data collection and analysis (Murphy et al, 1998). For example, Murphy et al, (1998) suggest that qualitative research be judged in terms of the use of systematic methods for coding and handling data. Underpinning theory, conduct, design and analysis of data are all considered to be important elements in judging quality and rigour (Mays and Pope, 1996). The tendency to make data appear more patterned than they are is a threat to

trustworthiness suggesting studies should include a search for and presentation of negative or deviant cases (Silverman 2001).

One example of making the process of analysis more transparent is by making data available to scrutiny. Interviews are a favoured method of data collection (Silverman, 1998a) and lend themselves particularly well to gaining rich authentic experiences of participants (Cutcliffe and Goward, 2000). Including contextualised extracts of interviews in published papers may help to establish the creditability and plausibility of findings (Hammersley 1992).

Given the small sample sizes of many qualitative studies it is the ability to generate theory that establishes its usefulness and papers were examined with this in mind. Findings from qualitative studies may not be directly generalisable, however theories developed from findings may have applications in other contexts (Murphy et al, 1998).

In addition, Murphy et al, (1998) have argued that it is important to relate qualitative data to the context of their production. This requires an awareness of the researchers' role in contributing to the data collected and the shaping of analysis highlighting the necessity for a reflexive approach that is clearly explicated. The ways in which qualitative research privileges respondents' versions of the world to the extent that it deals even-handedly with competing accounts and recognises the situated and context bound elements of the production of accounts is an important signifier of rigour.

Qualitative research must therefore describe the research process adequately (transparency), detail the steps taken to handle and analyse data (credibility), provide contextualised extracts of responses as a means of checking validity of interpretations (verifiability), explore deviant or negative cases (trustworthiness), make explicit attempts to theorise from the findings (transferability) and present accounts even-handedly (fair dealing).

Finally, research in forensic mental health services has to contend with a number of ethical problems. Many people receiving services are detained in secure facilities or living in the community and liable to recall to hospital. Conducting research with this group of service users can raise concerns about capacity to give informed consent, the validity of consent when detained, issues of control, power, privacy and confidentiality with the potential for exploiting for research purposes a literally captive audience. Although not a measure of quality, external scrutiny via a research ethics committee is an important safeguard against prurient, voyeuristic and exploitative research with this population.

FINDINGS

Interviews feature as the primary data collection tool and most studies in this review (13 out the 22 studies reviewed) employed semi-structured interviews either as the sole data collection tool (e.g. Byrt and Reece, 1999) or combined with standardised measures (Morrison et al, 1996) (See Appendix). Standardised or structured interviews of service user views have also been used. For example, Dell and Grounds (1995) conducted a structured interview study in addition to a comprehensive record study of conditionally discharged service users. Gerber et al, (2003), Ford et al, (1999) and Vaughan and Stevenson, (2002) used standardised interviews to allow data to be subsequently quantified and analysed.

Satisfaction with services (Ford et al, 1999, Huckle 1997; Morrison et al, 1996), satisfaction with mode of psychiatric evaluation (Brodey et al, 2000) and quality of life (Walker and Gudjonsson, 2000) have also been studied using standardised measures. Unique among the studies reviewed here, Quinsey et al, (1996) employed a control group to compare offender perspectives with those of nonoffenders, using standardised attributional scales.

Survey designs using self-report questionnaires were reported in three papers (Goodwin 1994; Hamilton Russell and McGregor Kettles 1996; Robinson and Collins 1995) and responses from these were subjected to thematic and content analysis.

A small number of studies report using theory driven methods such as grounded theory (Skelly 1994a; Schafer and Peternelj-Taylor, 2003 and Hinsby and Baker, 2004). Arigo (2001) employed an ethnographic case study approach and Sequiera and Halstead, (2002) report using the qualitative approaches of grounded theory and phenomenology.

Assessing Quality of Methods

Sample sizes ranged from an ethnographic study of 3 people (Arigo, 2001) to survey of 79 participants in a survey of Special Hospital patients (Robinson and Collins, 1995). Randomised samples were used by Quinsey et al, (1996) and Vaughan and Stevenson (2002). Some studies do not describe how sampling was achieved, for example Arigo, (2001, p.170) indicates only that his sample was of "three typical mental health citizens". Details of sampling are summarised in the Appendix.

A range of terms are used to describe samples. For example, Arigo, (2001) described his sample as mentally ill offenders, Ford et al, (1999) and Byrt and Reece, (1999) referred to in-patients and Dell and Grounds, (1995) to conditionally discharged patients. Brodey et al's, (2000) sample was described as forensic psychiatric patient inmates in an urban jail, and Quinsey et al, (1996) researched male mentally disordered offenders in a secure psychiatric setting. Schafer and Peternelj-Taylor, (2003) referred to offenders enrolled on a treatment programme as forensic patients. Vaughan and Stevenson's, (2000) study of prisoners in a category B prison referred to mentally disordered offender service users. Many other studies (Skelly 1994a;

Robinson and Collins, 1995; Hamilton Russell and McGregor Kettles 1996;

Morrison et al, 1996; Riordan et al, 2002) were of patients in receipt of

forensic mental health services who are not prisoners.

Transparency and Credibility

There is some variation across studies in describing the research process.

For example Riordan et al, (2002) indicated only that a qualitative approach

was used to analyse responses and did not provide detail of the qualitative

approach used or the process of analysis. It is therefore not possible to judge

the study with regard to its adherence to general principles of a particular

qualitative approach or its conduct for example, in relation to the coding and

handling of data. Some papers (Robinson and Collins, 1995; Ford et al, 1999;

Ryan et al, 2002) reported that content or thematic analysis was used to

analyse data but offer no description of this process.

Three of 22 studies in this review (Skelly, 1994b; Quinsey et al, 1996; Schafer

and Peternelj-Taylor, 2003) described the process of data analysis with

sufficient clarity to enable a judgement to be made about rigour and in each

case clear adherence to the principles of the chosen approach are reported.

Two studies (Ryan et al, 2002; Sainsbury et al, 2004) described using a

researchers blind to the objectives of the research to categorise interview data

and evaluate codings to enhance objectivity.

Verifiability and Trustworthiness

The use of interview extracts range from studies in which they are absent

(Hamilton Russell and McGregor Kettles, 1996; Brodey et al, 2000) through to

decontextualised short extracts (Ford et al, 1999; Riordan et al, 2002). In some cases this was appropriate to the method used such as standardised measures being used to obtain views (Quinsey et al, 1996; Walker and Gudjonsson, 2000; Gerber et al, 2003). In Arigo's, (2001) case study approach, longer contextualised extracts are reported. No studies in this review report exploring and studying deviant or negative cases to refine analysis.

Transferability

Few studies of service user views in forensic mental health explicitly theorise from findings although many recognise limitations in regard to generalisability. Skelly's (1994a,b) paper explicitly theorises to suggest alternative applications but this is unique among the studies reviewed. Quinsey et al, (1996), Walker and Gudjonsson, (2000) and Gerber et al, (2003) are appropriately cautious in seeking to generalise from findings.

Fair dealing

Only Arigo's, (2001) study explored the situated and context bound nature of the production of accounts rather than simply taking them at face value. Most studies in this review while indicating the service context of the production of accounts fail to discuss these in relation to what is reported or indeed in relation to alternate perspectives.

Ethical Issues

Six of the twenty-two studies explicitly state that ethics committee approval

was sought and a further 4 papers indicate that informed consent was sought from respondents. Vaughan and Stevenson, (2002, p.12) obtained "written agreement to be interviewed" from participants. There is no discussion on ethical issues in the studies reviewed.

Service user views

The range of views expressed by service users are summarised in the Appendix. Service user perspectives indicate that while detained in secure facilities the quality of the therapeutic relationship is of immense importance and dissatisfaction often relates to perceived deficits in these relationships (Byrt and Reece, 1999; Ford, 1999; Ryan, 2002). Professionals providing supportive yet challenging therapeutic assistance were considered most helpful (Schafer and Peternelj-Taylor, 2003) with the aim of addressing denial and improving motivation (Sainsbury et al, 2004). Institutional controls were often seen as punitive (Hinsby and Baker, 2004) and negative experiences of professional responses were reported in relation to self-harming behaviour (Byrt and Reece, 1999), control and restraint procedures (Sequeira and Halstead, 2002) and in failing to establish clear therapeutic boundaries (Schafer and Peternelj-Taylor 2003).

Concerns about restrictions on liberty were reported by those living in the community (Riordan et al, 2002) as well as those detained in hospital (Morrison et al, 1996). Better communication of information to inpatients was also highlighted (Skelly 1994a,b) with some suggesting more regular meetings between patient and allocated nurse (Hamilton-Russell and

McGregor Kettles, 1996). Those living in the community reported a sense of belonging despite poor integration (Gerber et al, 2003) and while many on conditional discharge orders found these helpful (Riordan et al, 2002) there was also a concern that these orders should ease-off over time (Dell and Grounds, 1995).

With regard to offending behaviours mentally disordered offenders rated their likelihood of re-offending as lower than matched non-offender controls and those who considered themselves less likely to offend were subsequently less likely to accept treatment aimed at reducing recidivism (Quinsey et al, 1996).

Discussion

The range of approaches used in studies reviewed include purely quantitative approaches (for example Quinsey et al, 1996), mixed methods (Hamiliton Russell and McGregor Kettles, 1996) and more purely qualitative approaches (Skelly 1994a, 1994b; Arigo 2001; Schafer and Peternelj-Taylor 2003). This range of approaches might suggest a healthy eclecticism contributing to our understanding of the service user perspective. The selection of methods is however often presented uncritically. Some studies adopt mixed methods, for example, Hamilton Russell and McGregor Kettles, (1996) study used a qualitative approach and then subjected responses to statistical analysis. Using a mix of quantitative and qualitative methods in this way is not without its problems as quantitative and qualitative approaches tend to be founded upon sharply different worldviews (Brannen, 1992; Coyle and Williams 2000).

Consistency in the application of particular methods or approaches to research is an important consideration and mixing different qualitative approaches can lead to problems. There is evidence (for example, Sequeria and Halstead, 2002) of what has been referred to as method slurring (Baker et al, 1992). This is the tendency to blur the distinction between various methods of qualitative research resulting in inconsistent research designs leading in turn to accusations of lack of rigour.

The majority of studies (13 of 22) in this review have used interviews to obtain data. Atkinson and Silverman's (1997) interactionist view challenges the emphasis placed upon the open-ended interview as the preferred choice of data collection among social researchers in health. Their concern is that much interview research is based upon contemporary romantic assumptions that interviews offer more authentic access to real life experience and the self. It is unlikely that interviews as a data collection instrument will be abandoned on this basis alone but researchers should at the very least express the limitations and assumptions of interview research.

Studies reviewed here have treated responses, and by implication language as a means for tapping internal states. Respondents are thus seen as vessels of knowledge and interviews as a means to access this knowledge and their real experience. Rather than representing real experience however, an alternative is to view language as constructing the social world. In such a view, instead of seeing the telling of experiences as one true account they can be recognised as being contextual, dynamic and produced to further particular

motives or purposes (Reicher, 2000). Maynard (1989) further indicates the positions respondents adopt may suggest alignments that are revealing about the choices people make about what they say. Atkinson and Silverman (1997) contend that analysing interactions will be more illuminative that using interviews to capture the persons' experience of an event. The clear implication here is a need to broaden the range of theoretical and methodological approaches to gaining perspectives of care.

Satisfaction with services is one area where there has been understandable interest in gaining service user perspectives. These studies suggest areas for further investigation but fail to account for concerns about patient satisfaction surveys (Rankin, 2003). For example, patient satisfaction surveys tend to favour the agenda of those asking the questions and often fail to account for non-responders who may be most dissatisfied with services. Further the notion of satisfaction itself is not examined and its treatment within these studies is assumed to be unproblematic. For instance, there is no attempt between researcher and respondent to determine a shared meaning of the concept. It is likely that the concept of satisfaction is socially constructed, has overlapping constituent elements and is liable to change over time. Studies of patient satisfaction should therefore be based upon an agreed definition of satisfaction, be cognisant of its situated nature and be longitudinal (Avis et al. 1995).

In many ways what services users say about forensic services is similar to that expressed elsewhere in the psychiatric literature (Rogers et al, 1993;

Adam et al, 2003). The importance of the relationship is often expressed and staff engaged in both formal and informal therapeutic intervention need to bear this in mind. Inadequacies in preparation for discharge repeatedly feature as a concern (Goodwin, 1994; Hamilton-Russell and MacGregor Kettles, 1996) and once discharged there appears to be recognition of the benefit of formal supervision at least in the initial stages (Dell and Grounds, 1995; Riordan, et al, 2002). Service users however remain isolated and are not integrated into the communities to which they return (Gerber et al, 2003).

Recipients of forensic mental health services are not a homogenous group. Studies focussing upon diagnostic groups (Ryan et al, 2002; Sainsbury et al, 2004) or location, for instance medium secure services (Morrison et al, 1996) and community (Gerber et al, 2003) did not present sufficient detail to determine similarities and differences between groups and settings. Given the particular needs of women (Byrt et al, 2001) and the over –representation and treatment of black and ethnic minority groups (Lelliot et al, 2001; Bennett Inquiry 2003) it is noteworthy that few studies have investigated these experiences.

The absence of longer contextualised accounts illustrating service user views is notable and whether this is due to constraints placed on researchers by research journals, the conventions of publishing or limited research material to support conclusions is difficult to determine. In some instances it clearly reflects the methodological emphasis of the study (Gerber et al, 2003) but it remains unclear why there is such a reluctance to support the findings of

interview research with extended examples of data when this would not be tolerated in quantitative orientated research.

Given the context of forensic mental health it is surprising that many researchers did not state clearly that their studies had received external ethical review. Moreover no studies in this review discussed ethical aspects of researching service user views. This seems an important omission when potential research populations are held literally captive and where concerns exist in obtaining free and informed consent to participate in research that addresses sensitive topics (Lee, 1993; Adshead and Brown, 2003).

Recommendations and Conclusions

Forensic mental health researchers have not yet accessed views of services in a sustained, systematic and critical fashion or in a way that represents the multiple perspectives of service users. This might be criticised as potentially conflating a social political agenda with a research agenda (Silverman 1998b) and health researchers may be particularly vulnerable to such a charge. Reflexivity is a frequent rhetoric in research and concrete examples are notable by their absence in this review.

A number of salient recommendations are suggested from this review. Firstly there is the question of definition; that is whose perspectives or accounts are being reported. This is not a case of which account should we value, or give precedence to. Rather who do we mean when we speak of 'prisoners' and 'offenders'; if we are to use research findings based upon

service user perspectives it is useful to arrive at a judgment about the transferability or generalisability of the findings. There is much heterogeneity among users of forensic mental health services and greater clarity is necessary in describing research samples. One such distinction is that researchers clarify whether the sample consists of participants who are receiving care for a diagnosed mental health problem as opposed to participants where the primary reason for intervention is criminal offending behaviour.

The potential of satisfaction surveys in forensic mental health has yet to be realised and efforts should be made when considering such an approach to involve participants in determining a shared meaning of the concept (Avis et al, 1995).

With noted exceptions, few studies identified the research method used, most failed to adequately describe this or to include interview extracts and those that did presented these in ways that were decontextualised, thus limiting our ability to make judgements about the quality of the research. Researchers investigating service user perspectives must strive to clarify their research methods, explain them more fully and apply them consistently to improve confidence in their findings.

The challenge is to produce credible research findings of service user perspectives with the expressed intention of using this to inform and develop forensic mental health practice. Accessing and representing service user

views in ways that shift the focus away from professionals and towards recipients of care is a step towards a more radical research agenda. Service users of forensic services are now initiating, designing, conducting and writing their own research. This review suggests that research with a service user focus conducted by professionals in this field requires a more systematic approach.

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