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Service User Satisfaction in a Low Secure Forensic Learning Disability Unit?

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Abstract

Despite an increasing trend of service user involvement in psychiatric research, few studies involving the recipients of secure care, or individuals with learning disability, were identified. It was argued that service users with learning disabilities detained in a secure hospital setting were an important source of information about the care they received. It was predicted that this group would provide a valid and useful account of their experiences and that concerns would be raised in similar areas to those that have been reported in other groups of service users. These included concerns relating to environmental conditions, therapeutic activities, quality of available information about care, and concerns relating to living with others.

Seven service users completed a semi-structured interview about their experiences of the care that they received. Data were analysed using content analysis in order to derive a series of key themes whilst acknowledging the individuality of participants' experiences.

Themes were identified relating to two areas: Detention and Treatment. Findings supported predictions that individuals with learning disability could give valid views about their treatment. There was overlap between the findings of this research and previous studies considering views of mental health/forensic and learning disabled service users.

Keywords: Learning disability, forensic, low secure, service user involvement, qualitative

Introduction

Recent trends in the growth of consumerism have resulted in increasing consideration of customers' views of services. This trend is reflected in health care, with NHS services being encouraged to consult service users (Judge and Solomon, 1993; Department of Health, 1999). National surveys, e.g. the Health of the Nation report (Department of Health, 1991) and the Health in Partnership Research Programme (Department of Health, 2004) testify to the importance now placed on user involvement as advocated by government (Pilgrim and Waldron, 1998; Minogue et al., 2005).

Although the involvement of service users in the evaluation of healthcare services is an area that has developed, traditionally little attention was paid to those in receipt of mental health services (Rogers et al., 1993). There was a sense that people with a diagnosis of mental illness or learning disability were not able to provide valid views (Weinstein, 1981). Goodwin, Holmes, Newness and Waltho (1999), however, argued for a moral obligation to include mental health service users in research. Furthermore, Crawford and Rutter (2004) point out that

the perceived risk of a lack of representativeness in mental health service users taking part in research was no different from that in other service users.

A quantitative approach to measuring quality of care has focused upon the concept of social climate (Moos and Houts, 1968). This approach has relied upon the identification of factors that are thought to influence the social climate within a setting and to consider how these relate to service user and staff satisfaction (Middleboe et al., 2001). Moos, Shelton and Petty (1973) proposed that social climate factors related to the broad themes of relationships, treatment programmes and system maintenance. Several studies using the concept of social climate have suggested a relationship with treatment outcome (Langdon, Swift and Budd, 2006). It is noted, however, that this research utilises a quantitative and reductive framework, and tends to have different aims than those of the current research, which is concerned with developing an understanding of the experiences of a specific group of service users.

A number of studies have demonstrated that important data can be generated by considering the individual experience of mental health service users. Raphael and Peers (1972) identified themes relating to the physical environment within hospitals, the quality of direct care and to hospital life in general. Participants were critical of the levels of background noise, lack of privacy and inadequate space in which to store personal effects. Although there was general satisfaction with the level of care received from medical/nursing staff, dissatisfaction was expressed with regard to information provided about diagnosis/treatment. Service users also reported that they felt bored, especially in the evenings and weekend, and that the quality of the buildings and food was poor.

Raphael (1974) considered service users' views of psychiatric care provided in general hospitals. Short-term patients reported a preference for receiving treatment in a general hospital, whereas longer-stay patients preferred specialist units. Service users complained that they felt intimidated when attending ward round meetings, especially when large groups of professionals were present. Subsequent studies identified boredom, activity levels, noise levels and the quality of buildings and food as common areas of complaint (e.g. Mayer and Rosenblatt, 1974; Shields et al., 1988).

Goodwin et al (1999) identified a number of themes in their analysis of mental health service users' views. In terms of the environment, service users valued the quality (or otherwise) of decoration and opportunities for privacy. The quality of food was criticised and participants reported that arrangements for smoking were inadequate. Service users suggested that they would prefer staff to wear name badges and to provide entertainment activities. They reported that unit rules appeared arbitrary and complained that they received limited information about their care.

Several studies considered therapeutic contact. Lack of information about diagnosis and treatment was identified as the most common criticism (Hardy and West, 1994), although studies highlighted that this view was not shared by all participants (Shields et al., 1988).

Fewer studies have considered service users' experiences of secure (forensic) hospital care. Moos (1987) developed the Correctional Institutions Environment Scale (CIES), an instrument designed to measure factors associated with the social climate of secure units. The CIES has been used in prisons and secure hospitals at every level of security (Langdon et al. 2006). Studies concluded that

service users' views are often different to those of staff (e.g. Morrison et al., 1997). These findings support the importance of allowing for expression of the individual service user's experience.

A limited amount of qualitative research was identified. Participants reported that the worst aspects of care in a Psychiatric Intensive Care Unit (PICU) were being detained and having to cope with other patients' behaviour (Wykes and Carroll, 1993). Flood et al. (1994), in a survey of service users' views of detention in a Medium Secure Unit, reported that most participants were 'moderately' satisfied with the care they received, their interactions with staff and their relationships with other service users. When female service users were asked if their needs were being met, however, half said that they felt lonely and isolated on a mixed ward. Furthermore, one third of female participants reported that they felt vulnerable and sexually threatened.

Morrison et al. (1996) reported similar findings to those in non-detained psychiatric service users. The quantity and quality of food was criticised and detained service users reported finding their time in hospital boring. Participants requested additional contact with staff and suggested that higher staffing levels would ensure that planned activities, including escorted leave, could take place even when staff were engaged in higher levels of observation for other service users. Positive comments were made about the information service users received about their care and their right to appeal against detention. Standard leaflets regarding right to appeal and the Mental Health Review Tribunal, nature and reason for Section, relating to Mental Health Act Commissioners Service and consent to treatment are routinely provided to detained mental health service users. Service users felt less well informed, however, about the processes for securing leave and in the time it took to deal with complaints.

Goodwin et al. (1999) found that service users reported that the lack of freedom to leave a locked unit and the experience of being detained under a Section of the Mental Health Act, 1983, left them feeling angry, dejected and desperate. Furthermore, service users who had experienced incarceration in the prison system often reported that they would have preferred to have been detained in prison.

Few studies were identified in which individuals with learning disability participated in a service user satisfaction survey. Studies considering the social climate in learning disability settings have identified staff morale/team dynamics (Jenkins, Rose and Lovell, 1997), staff characteristics including age, gender and level of education (Hatton et al., 1999a) and the organisational culture (Hatton et al., 1999b) as important in relation to outcomes.

Langdon et al. (2006) employed the CIES to explore the social climate in a low and medium secure unit for people with learning disabilities. Differences were identified between the views of staff and those of service users. Service users felt that they had greater involvement in the running of the unit and received higher levels of support than staff thought that they did. Service users, however, felt that the staff needed to rely on physical interventions and security measures more than staff thought that they did and were less positive in their views as to how much the treatment they received focused upon rehabilitation. The outcome of this piece of research again highlights the importance of full consideration of the individual experience when considering service user satisfaction.

Longo and Scior (2004) used a semi-structured interview protocol to explore the experiences of 36 individuals with learning disability who were in hospital at the time of their participation. Themes relating to a lack of control over basic decision making, lack of information about treatment and a perceived lack of support from staff were identified. Participants reported predominately negative views about generic psychiatric services. More positive views were reported with regard to specialist learning disability services.

The Current Study

The current study is an attempt to include service users detained in a low secure forensic unit for adults with a learning disability in a semi-structured interview exploration of their experiences of their care. It was predicted that they would be able to report clear views about their experiences. In order to facilitate this process a semi-structured interview procedure was developed and data were analysed using content analysis. It was hypothesised that themes relating to the environment (quality of food, décor), restrictions (locked doors, detention under Mental Health Act), levels of activity (boredom) and living with other people who could, at times, present with antisocial/challenging behaviours would be identified as sources of concern. It was also hypothesised that service users would be more positive about the therapeutic care they received.

Method

The qualitative study described used data from interviews with patients in a low secure forensic hospital unit for people with mild and borderline learning disabilities. Service users were asked to share their thoughts and feelings regarding the service they received, and to comment upon their experiences of detention within the unit.

Ethical Approval

Application for Ethical Approval was considered by the Research and Development departments of the host NHS Trust and by the Local Research Ethics Committee prior to collecting data. The proposal received favourable ethical opinion.

Participants

Seven service users, (5 of whom were male), took part in the research. All participants were detained under either Section 3 or Section 37 of the Mental Health Act (1983) at an eight-bedded low secure unit. Participants were all adults. All participants had received a formal diagnosis of learning disability; Full Scale IQ scores were within the mild/borderline range (the maximum was 75). Three participants were diagnosed with co-morbid psychiatric disorders. All participants had a history of behaviour that was 'against the law,' and all but one participant had formal convictions.

Researchers

The research team comprised five people; a Clinical Psychologist, an Assistant Psychologist, a Senior Nurse Manager, a Consultant in the Psychiatry of Learning Disability, and a Senior Practitioner in Forensic Social Work. All researchers worked at the service from which participants were recruited. The

role of the Consultant Psychiatrist was to guide the design of the study and have an overview of the analysis (including 'credibility checking'). The other researchers informed service-users of the opportunity to take part in the research, sought consent from those that expressed an interest in doing so, and gathered and analysed the data.

Procedure

Semi-structured interviews were conducted based on an interview schedule that spelled out the topics to be covered, but was sufficiently flexible to allow participants to talk about their experiences. The purpose of the semi-structured interview was to help the interviewer obtain in-depth information relating to the purpose of the study.

The semi-structured interview protocol was developed following consultation with all service users on the unit who were asked what factors they thought would be important if there was to be a survey of their views of the care they received. Service users were asked to 'brain storm' areas for consideration during the course of two open-forum groups that were facilitated by a Senior Nurse Manager and an Assistant Psychologist. Suggestions were then translated into open-question form and the semi-structured interview protocol was developed during the course of a meeting that was attended by all members of the research team. It was decided to develop the protocol in this manner in order to ensure that the areas included in the semi-structured interview were of importance to the service users and to ensure that the development of questions was not influenced by professional bias.

Each interview lasted between 30 and 60 minutes, and took place in a private consulting room. Prior to taking part in the interview, participants were asked if they would take part in a study regarding their views and experiences of their care. A third party was involved in seeking willing volunteers to ensure that potential participants did not feel obliged to take part as a result of being asked to do so by clinicians involved in their day-to-day care. Of nine individuals approached, seven agreed to participate. Confidentiality and anonymity were assured and maintained throughout all stages of the investigation. All the interviews were tape-recorded with the participants' permission, and transcribed verbatim.

Data Analyses

Data were analysed using content analysis, a method of exploring in detail the participants' views around the topic in question, and making sense of it through a process of interpretative activity that acknowledges the presence, and influence, of the researcher's own conceptions. Content analysis attempts to understand the content and complexity of the beliefs and constructs being explained or suggested. Themes were taken to indicate shared understandings between participants; however, the analysis also acknowledged the range and diversity of participants' individual responses.

In order to assess mutual agreement on themes, transcripts were rated independently by two raters, and a comparison was made between each rater's interpretation of the main emergent themes. In the following analysis, extracts from interviews were selected as being exemplary of the themes that emerged.

Results

Restrictions/Detention

Reason for Admission: It's punishment

All participants associated their admission to the unit with their offending behaviour:

“They put me on it in court... because of things that you do wrong.”

There was a sense, therefore, that detention at the unit amounted to a form of punishment rather than treatment:

“It's punishment.”

Detention: You can't go home

Participants identified frustration associated with their detention. This was often related to restrictions in family contact:

“I don't [have enough contact], I see them once a week (regarding parents).”

“When I came in here they cut it [parents' visits] down to two nights a week.”

Similarly, not being allowed to go on home visits, particularly at special times in the year, was identified:

“You can't go home for Christmas.”

Lack of control: It's the staff who control things

Participants described a number of restrictions upon their ability to control day-to-day things, ranging from looking after their money:

“It says ... [participant's name] not ... [staff's name] and they should not be able to touch that money. I think they are trying to run people's money in here.”

To looking after other possessions, in this case CDs:

“No one should have moved them without my permission.”

To controlling the light switches:

“It's the staff who control them [the lights]”

Participants appeared to find these restrictions frustrating and provocative.

Restrictions in terms of access to the community were also identified as a source of concern.

“I don't get enough of it [ground leave]”

Participants thought that this was unfair when they compared themselves to others:

“I can’t go [out] but if ... [another patient] wants to go, she can.”

Participants also expressed concern about the restrictions that were inherent to the forensic environment:

“Your stuff has to be locked away.”

“You can’t keep anything sharp in your bedroom.”

Food and drinks: It’s nice to eat but...

Furthermore, participants were displeased with the quality and quantity of food and drinks that were available:

“We don’t get enough drinks.”

“The fish is hard, the peas are hard and you can hardly chew on them.”

“It’s nice to eat, but I don’t like hospital food.”

Smoking: I want smoking to be banned in here

Participants demonstrated mixed views about smoking. At the time of data collection the Trust was in the process of changing its policies regarding smoking, and patients had been advised that there would come a time when smoking would no longer be permitted within the building. Several participants appeared to view this as a positive move:

“I want smoking to be banned in here.”

Others, however, were concerned that changes to smoking procedure would potentially result in anger and aggression:

“Patients like, if they haven’t got no cigs they get mad and when they smoke outside it will be a lot worse.”

Environment: I wouldn’t say that it is scruffy but I wouldn’t say that it is clean

Other factors of concern regarding the environment included the general appearance of the unit:

“I would like to see this place cleaned up a lot, good paint and new carpets.”

And the comfort of the bedding:

“Beds aren’t comfortable, the mattress is hard.”

“Bed is like a leather material which sticks to you.”

Other service users: The patients do your head in a bit

Participants noted that it was often difficult to live alongside their peers:

“The patients do your head in a bit.”

Examples of challenging behaviours were identified that contributed to the difficulties that individuals experienced within the shared environment:

“They smash cups, try to pull the TV off the wall, it’s mad.”

“When staff aren’t there she’ll turn around and say ‘give us a cig.’”

Some empathy and understanding was expressed, however, for other people’s difficulties:

“I feel sorry for her because she hallucinates sometimes.”

Mixed sex environment: It should be just men

None of the female participants in this study identified difficulties associated with a mixed-sex environment. Several of the male participants, however, stated that they found this problematic:

“It’s the lasses that kick off most, crying and swearing.”

Treatment

Therapeutic Activities: Treatment helps quite a bit

Specific forms of treatment were identified as being beneficial:

“Sessions about drugs, alcohol, anger management; they’ve all helped.”

“I’m at college, that has helped.”

Others were identified as being less positive:

“Art, that’s the one that I hate the most, I still do it but I don’t like it at all.”

Frustration was expressed when expected therapeutic activities did not take place:

“I was told [that in] two weeks time I was going out to ... [external day centre] but I haven’t been down there yet.”

There was also an indication that therapeutic sessions could be difficult:

“Opening up to you [Psychologist] makes me a bit upset.”

Progress: ‘this lad’s done really well’

Participants were positive about the progress that they thought they had made since admission to the unit:

“I do think people have helped me here.”

“I used to wind people up but I don’t do that anymore.”

It was also apparent that participants hoped that the progress they had made would help them to move on from the unit:

“You might think ‘this lad’s done really well’ and you might move me somewhere.”

Meetings: It’s a bit scary...

Participants reported that there were aspects of the therapeutic regime that they found stressful. For example, all participants commented about attending weekly Clinical Team (‘ward round’) Meetings:

“I do get a bit shaky in there.”

“I get butterflies before I go in.”

This anxiety related to times when large groups of professionals were in attendance:

“It’s a bit scary when there are lots of people in there that I don’t know.”

Participants were concerned that material discussed during the course of multidisciplinary team meetings may not be confidential:

“She could send [confidential notes] anywhere.”

Participants felt frustrated that access to multidisciplinary team meetings was limited:

“I usually get called in sometimes, but I can’t understand why he (RMO) doesn’t call me in all the time to see him.”

“I have a little say [in the MDT meetings] but I have to go before I’ve finished what I were saying.”

Similarly there was some confusion as to the specific purpose of the meeting:

“I don’t really get much chance to see them. They just want me to tell them what I want and then I have to go.”

Relationships with staff: He’s been good

Some frustration was expressed that individuals were not allowed to select which members of staff they would work with:

“[I was] shocked [that] I didn’t get to choose my care team.”

Participants reported that time with staff was sometimes limited. This included both direct care staff and members of the wider multidisciplinary team:

“I can understand that they are busy but I have to wait to have a word with them.”

“They’re busy all the time, it would be nice to meet with them more often.”

Relationships with staff were often described in positive terms and examples were given of how staff had been able to help:

“I’ve talked to staff and they have helped me.”

These examples also extended to members of the wider multi-disciplinary team:

“[RMO] he’s been good.”

Participants also noted examples of less-helpful behaviour from staff. This included staff making personal comments:

“She takes the micky out of me saying, ‘what have you had your hair cut like that for?’... they shouldn’t be talking to us like that.”

Participants recognised that there was a hierarchy within the unit staff and that they could use this when they were concerned about specific members of staff:

“If it gets worse I’ll call... [Unit Manager or Deputy Manager] in and report them.”

Advocacy: He can help me more than anyone

Several participants described positive experiences of the hospital advocacy service:

“He [advocate] can help me more than anyone.”

Others, however, were less positive:

“They say they’re doing everything for me to get out, but I don’t think they are.”

Discussion

The results of this research indicated that, not only were the participants able to comment about the services that they received, but they were able to provide a large quantity of high quality material. This was consistent with previous findings concerning the involvement of mental health service users (Crawford and Rutter, 2004; Goodwin et al., 1999) and people with learning disabilities (Longo and Scior, 2004) in the research process.

It was predicted on the basis of similar research that the themes of the living environment, restrictions in freedom, the general activity level and stress related to living with others would be reported by service users as sources of concern. Analysis of the data collected indicated that themes could be divided into two categories: Restrictions/Detention and Treatment.

Restrictions/Detention

Themes that related to detention in the unit were grouped under this domain. There was a sense that admission to the unit amounted to a form of punishment and was the result of their offending behaviour. Participants described a number of restrictions associated with life on the unit, including the negative impact of restrictions in access to their families. Frustration at losing access to friends and family is commonly encountered within forensic settings and has been reported in research as a source of anger, desperation and dejection (e.g. Wykes and Carroll, 1993; Goodwin et al., 1999). One wonders if the effect of such restrictions is felt especially strongly in learning disabled individuals, who may have been more dependent upon family and may have been more likely to have lived within the family home into their adult lives. The importance of facilitating family access wherever possible and of assisting in-patients groups in maintaining contact was noted.

Participants described frustration at losing control over many activities that we take for granted. It was noted that losing control over areas from turning on lights and deciding when to have a hot drink, to deciding when to go out and managing one's own finances, had a significant effect upon the individual's sense of well-being. Goodwin et al. (1999) suggested that this kind of loss of freedom resulted in individuals experiencing negative emotions including anger and dejection. Longo and Scior (2004) identified that this was an area of concern reported within non-forensic learning disabled service-users. Although risk management inevitably includes a degree of control, the findings highlight the importance of remaining mindful of the effects that this has upon the individual. Further research into the effects on the individual's sense of self of such restrictions is indicated.

Previous research indicated that factors relating to the environment and food were of paramount importance to hospitalised (e.g. Raphael and Peers, 1972) and detained (e.g. Morrison et al., 1996) service-users. As predicted, these factors were identified as a source of concern. It was interesting that participants, all of whom were cigarette smokers, described a mixed view about smoking within the unit, with several individuals suggesting that it would be preferable for this to be banned. The differing views perhaps reflected the ambivalence that is characteristic in cigarette smokers. Given proposed changes across the trust that would result in all buildings becoming 'smoke-free', it was reassuring to note that service users recognised negative consequences to their smoking within the unit.

Living with other service users was identified as a source of frustration, anxiety and fear. Examples were provided of potentially frightening and destructive behaviours and there was a sense of helplessness in this respect. Indeed, one participant suggested that the service users should be issued with the same personal alarms as staff wore. Wykes and Carroll (1993) found similar concerns.

Interestingly, vulnerability was not associated with the unit being mixed gender. Members of staff working on the unit were acutely aware of the risks associated with managing potentially predatory individuals in a mixed setting. High levels of observation were maintained and individualised care plans implemented when necessary. It is suggested that these interventions had helped service users to feel protected.

Treatment

The second group of themes related to treatment within the unit. As predicted prior to collecting data, participants valued the treatment that they received. Every effort was made to support treatment within the unit and a strong rehabilitative philosophy underpinned this. It was pleasing, therefore, that participants felt that they had changed as a result of treatment. It was striking that potentially difficult (upsetting) aspects of treatment were also acknowledged. There was a realistic understanding that treatment could be difficult. Furthermore, progress in therapy was associated with the prospect of moving on from the unit and there was an understanding that treatment would help them to return to the community.

Participants reported that they found attending multidisciplinary team meetings and reviews intimidating and 'scary'. As was the case in earlier research, (e.g. Raphael, 1974) having large numbers of staff present in meetings increased anxiety. It was also identified that uncertainty about when meetings would take place, and at what time service-users would be invited to join the discussion, added to the frustration. It is recommended that the structure of team meetings is reviewed with this in mind and that every effort is made to help service-users to benefit from this forum. Recommendations include limiting the number of staff attending meetings and improving time keeping such that service-users are not kept waiting. It is acknowledged that these difficulties are not unique to learning disability or forensic care.

Service-users reported both positive and negative experiences in their relationships with staff. A lack of support from staff, as reported by Longo and Scior (2004), was also reported in this study. Most notably, participants were aware of the time pressures that staff were under and described how this often impacted upon the level of care that they received. The importance, therefore, of high levels of staff support was noted. More positive comments were made and examples were provided of the ways in which staff had helped. Similarly, the advocacy service was mentioned as a helpful service, although one participant expressed some doubt as to the degree to which the advocate was trying to help her to 'get out.'

Critique

This study aimed to consider service user satisfaction by gathering the views of a small number of participants who had received in-patient care in the same unit. In some respects the strengths of this study, as a piece of research, in terms of providing a deeper understanding of individual experience without limiting the breadth of the data by relying on the set format of a questionnaire, also reflect its limitations. The study was limited to gathering the views of just seven individuals and the findings focused specifically upon their individual experience. This research did not aim to generate findings that could be generalised, although it was noted that the findings did resonate with those of other studies.

The study aimed to employ a robust research methodology to allow for analysis of the data that fully represented the individual nature of the data. Plans had initially been made to make use of Interpretative Phenomenological Analysis (IPA) as a means of data analysis, but reconsideration of how the data were treated indicated that IPA had not been employed in its true sense and that the actual level of analysis was content analysis. Every effort was made to control for

bias and data were scrutinised by two researchers as a means of checking the validity of interpretations. An alternative approach would have been to utilise IPA and to stress the inevitable influence of the researcher in the write-up.

One of the true strengths of this study has been to generate ideas for further research with this group of individuals. One such idea would be to gather the views of staff of the care that they provide and to see how these compared with those of the service users. Other important follow-ups include involving service users at different times in their treatment, and the possibility of including a quantitative element to this type of research, perhaps making use of the social climate research via the CIES.

Conclusion

Readers of this article could be forgiven, while acknowledging the essentially good relations between staff and patients, for concluding that a number of the patients' criticisms seem reasonable and that even this small low secure unit is far too institutional in its approach to the care, rather than the punishment, of patients. From staff controlling light switches and patients' monies; from the failure to give sufficient information about diagnosis and treatment; from the boring nature of food off the hospital trolley and the scuffed and grimy appearance of the unit environment: all give testimony to the derivation of this and other such units from the mental handicap hospitals of old.

It is not, according to these views, a matter of practice by nursing and other staff. It seems more a matter of a unit-wide policy of control and restraint which extends far beyond the occasional physical intervention and seclusion. These comments suggest the need for:

- A more open unit.
- Not necessarily no locked doors but fewer locked doors.
- Higher expectations of patients and a more domestic environment.
- A more educational and less proscriptive approach.
- More discussion with patients and less assumption of compliance.

The unit may need to move more in the direction of the hostel and even further away from the prison. These views on service provision in this low-secure unit for people with a learning disability must be taken seriously – they are not extreme and sound all too reasonable.

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