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## **Title: What factors influence carers of forensic mental health in-patients satisfaction with services?**

### Abstract

#### Background

Families are the main caring resource for service users with severe mental health problems. There has been limited work examining the needs of carers of people using forensic mental health services.

#### Aims

This study aimed to gain an understanding of carers satisfaction with services in forensic mental health inpatient settings.

#### Method

A survey design was used with 63 carers interviewed by telephone using a structured interview schedule. The data was analysed both qualitatively and quantitatively.

#### Results

Most carers were pleased with the service provided although some negative views were expressed with specific types of contact. Giving appropriate information to carers was strongly associated with satisfaction with the service being provided.

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## Conclusions

Carer satisfaction with forensic mental health services is likely to be higher with services that address carers' information needs. New ways of providing this information may offer greater opportunities for working with carers.

## Declaration of interest

None

## **Background**

In the United Kingdom, families are the main carers for users of forensic mental health services (Absalom et al (2010). This makes practical, physical, psychological and emotional demands on the carer potentially resulting in high levels of distress. However, many people with a mental illness could not continue to live independently without carers and the overall cost of community care would be much higher (Lelliott et al, 2003).

The Best Practice Guidance for Medium Secure Units (Health Offender Partnerships, 2007) stated carers should be involved in the care process as much as possible while NIHME (2004) maintained forensic services build mechanisms that involve carers and respond to their views. However, there are a scarcity of reports examining the needs of this group of carers (Canning et al, 2009; MacInnes and Watson 2002; NIHME 2004) though recently Absalom and colleagues have published some papers looking at the potential for family interventions in secure settings.

The findings from these few studies indicate carers of forensic mental health service users face increased levels of stress compared to non-forensic carers

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(MacInnes and Watson, 2002; NIHME, 2004). Additionally, the pressures faced by carers may strain their relationship with users leading to reduced support and contact (Canning et al, 2009). Canning et al's (2009) survey of 38 medium and high secure units found most provided some form of carer support but this varied in the type and frequency offered and noted concerns that some services did not understand the needs of this group of carers.

This study examined the carers' views of services aiming to gain an understanding of the experiences of carers of patients in a forensic mental health inpatient setting and specifically:

- rate carers satisfaction with services,
- examine which factors were associated with satisfaction with services.

During the entire course of the study a group of carers, of users of forensic services, acted as an advisory group to the research team.

### **Method**

#### Design

A cross-sectional survey approach, with qualitative and quantitative data being collected, provided a "snap-shot" of the views and experiences of carers at a particular point in time (De Vaus, 2001).

#### Sample

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The study was conducted across two forensic medium secure units (MSU's) in London and South East England. One unit services a predominantly rural/urban population and the other urban London boroughs. All the carers from both units were eligible to be included. Every service user was informed about the research and had the option to discuss any concerns. No carer was contacted without service user consent. One carer per service user was asked to participate. Carers were determined as the person named by the service user as their closest supporter. The clinical team then confirmed this information. Once permission had been obtained, carers were contacted with information about the project. Data was collected by telephone interview as this was viewed as the most effective way of accessing as many carers as possible (De Vaus, 2001).

### Data Collection

A structured interview schedule was developed following extensive consultation between the researchers and the carer advisory group. Seven factors were identified: (1) experience of prior mental health services, (2) experience of their relative/friend moving to a MSU, (3) the information received from services, (4) the psychological impact of caring, (5) the ward environment, (6) involvement in their relative/friends's care and (7) discharge planning.

The carers were asked to rate their response regarding each factor on a five-point Likert type scale. The ratings were reflective of their positive or negative experiences with services in these areas, with 1 indicating a very negative experience, through to 5 indicating a very positive experience. Following each

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rating, the participants were encouraged to qualitatively expand on their answers with their responses written down by the interviewer. This may have resulted in the loss of some data when compared to audio recordings but the main comments written down were accurate as interviewer was able to clarify their validity during the interviews with the carers. The questions were structured with each respondent presented with the same questions in the same order to help ensure reliability, generalizability, and validity (Oppenheim, 2001). At the end of the interview, the carers were asked to rank their overall satisfaction with the service on the 1-5 Likert scale noted above and for any other comments about their contact with the service.

The interviews were conducted by a researcher not known to the respondents. This allows respondents to feel relaxed and express more realistic viewpoints (Silverman, 2008). Prior to undertaking the study, the interview schedule was piloted with three carers to test the applicability of the interview and the procedures for collecting data. The interviews were conducted over a period of six months in 2010/11 lasting for an average of 40 minutes.

### Analysis

The data were analysed quantitatively and qualitatively. Demographic data and mean rating scores were recorded descriptively. The association between the seven factors identified by the carer advisory group with the carers overall satisfaction score was then examined by Spearman correlation co-efficient. Cohen's (1988) conventions were used to interpret the strength of the

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relationship with a correlation coefficient of 0 – 0.29 representative of a weak or small association; a correlation coefficient of 0.30 – 0.49 a moderate correlation; and a correlation coefficient of 0.50 or larger representing a strong or large correlation.

All the qualitative comments were coded to “a priori” themes based on the seven factors rated by carers. The aim was to identify data relevant to each theme to illuminate the carers’ experiences and the reasons for the recorded ratings.

Approval to conduct the study was received from the University ethics committee and also from the relevant R&D department at each Trust.

### **Results**

Sixty three carers were interviewed corresponding to 40% of the service user population. The main reasons for not contacting carers were the service user or clinical team not wishing the carer to be contacted - 43 (27%) or no contact details for a carer available – 38 (24%). The vast majority (47) (75%) of the carers interviewed were parents. Of these 40 (64%) were mothers, consistent with the finding of other studies (Lefley, 1996; MacInnes and Watson, 2002). T-tests were undertaken on the demographic data to examine differences between the two units, and between parents as opposed to other carers, in their levels of satisfaction for the seven factors and overall satisfaction. No significant differences were recorded in satisfaction scores between the two units. Parents recorded lower levels of satisfaction compared to other carers on all categories except prior experience of mental health services. In two of

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the factors (move to forensic service and information provided by the service), these differences were statistically significant.

The ratings for the seven factors and overall service satisfaction are shown in Table 1. The mean score for each area is noted (with standard deviation in parentheses).

(Table 1 here)

A mean overall satisfaction score of 3.9 indicated carers were generally pleased with the services being provided.

The correlation between each of the seven factors with overall satisfaction is shown in Table 2. The rho score for each correlation is shown (with the p value in parentheses). Six factors were positively correlated with a positive overall view of the service. The only exception was discharge planning which recorded a very low negative correlation with overall service satisfaction.

(Table 2 here)

Previous experience of mental health services – The mean rating for this factor was 2.79, the joint lowest. The reason given by most respondents for a low score was there had been little communication or attention paid to their needs from generic mental health services, or other services such as the police or courts. This was noted by Carer 35, “they just wanted to get rid of

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*him....he was trouble*". This factor had a weak correlation with overall satisfaction with the service ( $\rho = 0.13$ ).

Move to forensic service – A mean rating of 3.83 reflects the view that the move to the forensic service was viewed positively by most carers as exemplified by Carer 23, *"At last his mental health problems have been recognised...he'll get the right treatment."* There was also a moderate correlation with overall satisfaction ( $\rho = 0.41$ ) suggesting this initial contact may have helped develop an overall positive relationship with the service.

Information provided by the service - This was viewed reasonably positively by the carers with a mean score of 3.25. Importantly, it was the only factor strongly correlated with overall satisfaction with the service ( $\rho = 0.67$ ). The carers made a number of comments about the types of information and support they thought was needed. Carer 7 stated *"I want to be able to get told about what's happening quickly.....how xxxx is getting on"*, while carer 17 suggested *"it would be helpful if I had a regular progress report or telephone call telling me how things were going"*. Other carers wanted practical information about the facilities at or near the unit such as *"I just want to know where to go to have a drink"* Carer 12.

Psychological impact of caring – This rating of 2.97 was near to the mid point score of 3 suggesting an overall "neutral" rating with some carers reporting they faced many pressures whilst others suggesting the caring role had little influence on their psychological health. There was a moderate association

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between this and overall satisfaction with services ( $\rho = 0.34$ ). Experiences recounted included, *“He told me he hated me, he hated his sister, he hated xxxx (key worker) and that he was going to stab someone... I didn’t know who to talk to, what I should do”* Carer 2. An alternative perspective was reported by Carer 14 *“xxxx (name of therapist) helped me and the family work out our problems”*.

Ward environment - The carers rated the ward environment very positively with a mean score of 3.86 though there was only a weak association between the environment and overall satisfaction with services ( $\rho = 0.28$ ). Most carers viewed the environment as pleasant to visit noting *“It’s usually got a nice atmosphere..... sometimes we have a laugh with other patients on the ward”*, Carer 44.

Involvement in care – This factor received the joint lowest rating (2.79) indicating a slightly negative view of their involvement with their friends/relatives care. There was a moderate correlation with satisfaction with services ( $\rho = 0.41$ ). A number of carers commented on their limited involvement in the care and treatment decisions made by the service as expressed by Carer 37 as *“I know xxxx better than anyone else... I would be able to be involved in planning his care. I’m going to be the one who he lives with once he leaves the xxxx (name of unit) so why can’t I say what I think he needs”*?

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Discharge plans – Carers were generally positive about the proposed discharge plans and their involvement in these discussions with a rating of 3.8 as noted by carer 27 who stated *“I know what’s happening ... and where they’re going..... and what support he’s gonna get”*.

However, only twenty carers answered this question. Other carers stated they were unable to answer as their friend/relative was not at the stage where discharge was being considered. Overall, there was a very low negative correlation with overall satisfaction ( $\rho = -.05$ ).

### Other Comments

Some carers suggested it would be helpful to meet other carers to offer reciprocal support. *“I would really like to meet up with other carers....we used to.... at the annual fete and it was good to talk to other people in the same boat”*, Carer 16. However, many were unsure as to how this could be organised with a common problem being described by Carer 56. *“I don’t want to join a carers group. I can’t attend much as they happen in the evenings and they are at the xxxx (name of unit) and I can’t get there at that time”*.

### Discussion

The overall satisfaction scores signify carers are generally satisfied with the services they receive. However, it has been noted general ratings tend to produce higher levels of satisfaction and fail to provide information about specific areas of dissatisfaction (Williams and Calnan, 1991). When examining the seven specific factors there were positive ratings for; the move to the forensic service, the ward environment, and the discharge plans with

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slightly negative ratings in two areas; previous experiences of mental health services and involvement in their relatives/friends care. Arguably, the most important finding is that one factor (information provided by the service) was strongly associated with service satisfaction. A moderate positive correlation was found with three further factors; move to the forensic service, involvement in care and the impact of their psychological health.

Providing valid information and support to carers is in keeping with the views expressed in official reports (Department of Health, 2008; Triangle of Care Report, 2010). Many carers in this study reported not knowing about ward routines and procedures, not understanding their friend/relative's diagnosis, their medication regime, procedures for gaining leave or applying for Mental Health Review Tribunals. Other studies of forensic services have reported similar findings. Canning et al (2009) found the majority of services mainly provided support in the form of information leaflets while just over a quarter (26%) provided no support for carers. Absalom et al (2011) also found about half of forensic services surveyed reported difficulties in establishing and maintaining support.

The carers' comments in this study stressed the importance of having ongoing contact with the service that was quick, reliable and efficient. Other studies have found greater contact with services is associated with an improved relationship and quality of communication (Canning et al, 2009) as well as a better understanding of the illness and the reasons behind decisions made by clinicians (MacInnes, 1999). MacInnes (1999) also found greater understanding of the illness was associated with more positive coping

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responses by carers with McCann et al (1996) noting a lack of knowledge led to a misattribution of the user's behaviour resulting in poor coping responses.

The finding that parents recorded significantly lower scores than other carers regarding receiving information suggests it may be beneficial for services to target their information and support needs. A liaison worker whose primary role is to provide carers with relevant information and support may help deliver a more comprehensive and consistent service. However, only 2 out of a total of 38 units surveyed by Canning et al (2009) had a dedicated liaison worker.

Carers also commented that traditional methods of holding carer group meetings to impart information and support are limited. Concerns about the time and location of group meetings were also raised in Geelan and Nickson's (1999) study. In addition, many carers noted that they did not like their relative/friend to be aware that they were attending formal groups. This combined with Canning et al's (2009) finding that there were logistical problems associated with arranging carer groups suggest an alternative approach may be beneficial. Absalom and colleagues (2012) work using a web camera and internet link successfully provided family support and formalised family work and may offer an alternative approach.

Involvement in the care and treatment of their relative/friend can be viewed as an important consideration for services as it was the joint lowest ranked factor for satisfaction and recorded a moderate correlation with overall service satisfaction. These findings suggest that carers have some unhappiness with their level of involvement in the care approach. Studies in non-forensic

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settings have suggested that mental health services consistently overlook carer's abilities and offers of support in favour of professional skills (McCann et al, 2011). This negatively impacts on a carer's contribution to their relative/friends care. Absalom et al (2010) found a high number of forensic patients had on-going contact with relatives with 56% of relatives involved in the patient's discharge planning. This might be an important area for services to examine when working with carers, especially in the pre-discharge phase. The carers in this study appear to have been more positive about their views of the discharge arrangements and it may be that services are more likely to involve carers when a more clearly defined discharge plan has been developed. The fact that only a moderate association was recorded even though the factor was negatively rated might be an area for further exploration.

The impact of the caring role on psychological health was also moderately correlated with satisfaction with services. Absalom et al (2010) state family interventions in mental health help families cope with the burden of having a relative with schizophrenia and successful family interventions reduce in-patient stay and increase engagement with services. However, Absalom et al (2010) found only 7% of clinical staff were trained to deliver family interventions in forensic settings and less than half of these received clinical supervision. Geelan and Nickson (1999) concluded there were too few family workers, an absence of suitable venues, and a lack of staff time to conduct family work. This might be partly due to institutional resistance to the introduction of family work in forensic settings such as a lack of awareness of

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the evidence base supporting its use or reluctance to acknowledge limitations in the current service (McKeown, 2007). Lindon (2007) added that specific interventions may be more acceptable to carers when the requirements of the carers are also considered.

The move to the forensic service was moderately correlated with service satisfaction. This also recorded a high ranking, and appears to be partly associated with the carer's happiness of the admission to the two units, and getting away from their difficulties with other services. However, creating a good initial impression may be important to differentiate the forensic service from previous experiences with other services. As such, it presents a positive view of the service to carers and helps create an atmosphere where a constructive relationship can develop.

The other negatively ranked factor was the carers' previous experiences of mental health services. However, this had a low correlation with overall satisfaction. This is not surprising given that it was not associated with the current service being provided. However, it may be useful to create a positive impression following admission to emphasise the positive nature of the service and reduce any on-going concerns. It also suggests that carers would benefit from a greater input from clinicians in mainstream mental health services and those working in criminal settings such as prisons or court liaison.

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### Conclusion

The results indicate that the majority of carers were positive in their views of services. However, some carers recorded negative views of specific aspects of their contact with services. The findings suggest that providing regular and appropriate information was the most important factor associated with carer satisfaction with services. It is proposed that developing services that address these information needs will lead to greater carer satisfaction and increased engagement with forensic mental health services. Examining new ways of providing this information and support, through individual liaison workers or web based communication may offer greater opportunities for working with carers. Future work using a purely qualitative approach may also give a greater in-depth examination of the experiences and perceptions of carers.

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