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action for people affected by mental illness

EXPLORING FAMILY CARER INVOLVEMENT IN FORENSIC MENTAL HEALTH SERVICES

Discussion and Summary

University of Central Lancashire

Support in Mind Scotland

Forensic Mental Health Services
Managed Care Network

STUDY EXPLORING FAMILY CARER INVOLVEMENT IN FORENSIC MENTAL HEALTH SERVICES IN SCOTLAND

EXECUTIVE SUMMARY

Background

Scottish policy and law underline the importance of supporting family carers and using their knowledge and experience to increase the effectiveness of mental health care and treatment. In particular, the Mental Health (Care & Treatment) (Scotland) Act 2003 (MHCT Act), and *Caring Together*, Carers Strategy for Scotland (Scottish Government, 2010), emphasise involvement and participation of carers in mental health services. While there is a growing body of research about carers' experiences generally, the needs and experience of those who support individuals in forensic (secure) mental health services (forensic carers) have been neglected. Support in Mind Scotland (SiMS) and the Forensic Network thus commissioned this independent study to examine what they identified as 'significant gaps and inconsistencies', focusing in particular on the views and experiences of forensic carers.

Purpose of Study

The study aimed to provide evidence about:

- Existing support for family carers across forensic mental health services in Scotland
- Any gaps between what professionals say is provided and carers' experience
- The extent to which carers access available support in forensic mental health services
- What works well and what hinders carers from accessing this support

In addition to gathering information from carers about their experiences and views, the study has gathered information from forensic mental health services about existing support, as well as about access and uptake.

Methods

The study used a range of mainly qualitative methods, and an appreciative or capacities approach, in gathering information about the aims and objectives including:

1. A review of literature focusing on innovative and best practice;
2. A questionnaire survey auditing forensic mental health services' practice in supporting carers;
3. A questionnaire survey of forensic carers;
4. In-depth qualitative interviews with carers.

Samples

All forensic mental health services across Scotland were surveyed, achieving a response rate of 79%, with varying levels of response across different parts of Scotland and the State Hospital. Sixty six responses were received from family carers or friends to an online and paper questionnaire, and 19 individual carers were interviewed face-to-face.

Key Findings

Forensic mental health services' perspective

In summary, the survey of forensic mental health services' perspectives of carer support found:

- Most forensic mental health services report that they identify carers when a patient is admitted to the ward or service, or as soon as possible thereafter.
- Levels of patient/carer contact were thought to vary, although staff estimated that an average of 69% of patients were in contact with their relatives. This was mainly by telephone or when their relatives visited.
- Services reported wide-ranging levels of carer involvement in CPA meetings, with a reported average of 53% across forensic mental health services.
- Services reported providing at least one form of support to carers, even if only providing information leaflets.
- The most common form of support reported by services was a link with the named key worker or nurse for the relative. Carer support groups and behavioural family therapy were less frequently available.
- Carer support is promoted mainly through direct communication, but staff also highlighted that they provide information leaflets, posters, and write out to carers about the support available.
- The decision to provide support to carers was most strongly associated with specific service drivers, such as legislation and policies.
- Face-to face consultation with forensic carers about what support they wanted was mostly non-existent, and a fifth of services had no mechanism for monitoring or evaluating the support they offered to carers. There were exceptions such as the State Hospital's annual survey of carers.
- Staff in services estimated that an average of 43% of carers engaged with the support they provide, with variations ranging from zero to 100% carer engagement.
- Half of the services reported experiencing some difficulty in providing carer support, which included low or no involvement in carer support groups they had initiated.
- Staff believed that many forensic carers were not interested in engaging, or were not in contact with their relatives or friends, thus complicating attempts to engage with them.
- Low uptake therefore was primarily explained in terms of carers' choice or circumstance and/or the stigma associated with caring for a relative in forensic mental health services. Having to travel long distances to visit someone in these services was another main reason why they thought carers did not engage with the support provided.

Experience of being a forensic carer

The survey and interviews with carers resulted in the following key messages about the experience of being a forensic carer:

- The term 'carer' did not sit easily with this group; many rejected this label and preferred to call themselves 'supporter', 'visitor', or simply referred to the nature of their relationship with the person such as 'mother', 'brother', 'sister', etc.
- Some said health professionals did not consider them to be carers when their relative entered forensic mental health services.
- However, a distinct role and sets of circumstances emerged that suggests it is useful to collectively refer to people in this situation, e.g. as 'forensic carers'.
- The forensic caring role was difficult to define, but at its core involved practical and emotional support provided to relatives or friends across different secure settings. Forensic carers carried a significant emotional burden.
- There were important differences between the experiences of forensic carers who were relatives and those who were friends of the person. Caring as a friend rarely brought the same emotional turmoil that close relatives described, nor was it felt by friends as important for them to be kept informed about care and treatment issues.
- Many carers reported not being listened to when raising concerns about their relative's deteriorating mental health prior to admission to forensic services.
- Carers commented on tangible improvements within forensic services in recent years. Some, however, commented that there was still some way to go before the individual needs of their relative were met.
- Feeling stigmatised was highlighted as a challenge for forensic carers, some losing friends and becoming isolated in their own communities.
- The impact of being a forensic carer was profound, impacting on all aspects of people's lives including their physical and mental health. For some, being able to share the responsibility for care helps mitigate the stress felt.
- Forensic carers had extensive experience of the named person role. Fifteen out of 19 people interviewed and 63% of survey respondents were, or had been, a named person for their relative or friend.

Forensic carers' experience of support

The survey and interviews with carers resulted in the following key findings about forensic carers' experience of support:

- Just short of half of survey respondents rated the quality of support received from forensic mental health services as either good or very good. However, nearly a fifth felt this was poor or very poor.
- A third of survey respondents had found it either easy or very easy to access support when they needed it, in comparison with around a third who had found this difficult or very difficult.
- Only just over a half of survey respondents had received any form of advice, information or support when their relative was first admitted to forensic mental health services. There was evidence to suggest this could, in part at least, be attributed to historical rather than current experience.

- 70% of survey respondents were aware of a carer group, though fewer attended one.
- Carer support groups played an important role in supporting carers, although geographically-based groups felt less relevant to some carers supporting relatives in high or medium secure units located elsewhere in Scotland.
- Over half of survey respondents did not know about independent advocacy support for carers, and of those who did, the majority said they had never been offered it. Only around one in ten said they had used an independent advocate.
- Carers valued interactions with staff with good interpersonal skills, empathy and insightfulness and who made time to talk with them. The importance of face-to-face contact was emphasised: few forensic carers valued written information above the chance to talk, listen and question.
- Slightly less than two fifths of survey respondents had received information indicating their rights, such as to a carers' assessment. Even amongst these, some felt this information had been 'too little, too late'. Three fifths of respondents rated the information as either good or very good, but a fifth said it was either poor or very poor.
- Forensic carers wanted to be listened to and respected more by services, and to get the information they need. Where individual professionals were seen to communicate actively and positively with carers, this was hugely valued.
- Almost half of survey respondents had experienced challenges in travelling to and from forensic mental health services and 44% had been challenged by the lack of flexibility around visits.
- Forensic carers in this study reported feeling frustrated and blocked in their attempts to access information, from hospitals in particular, but also failing to get replies from agencies such as Mental Welfare Commission for Scotland. Issues surrounding confidentiality were also a barrier.
- The factors that can impact on the frequency and quality of visits include distance to and from forensic units and ease of travel; the environment and having a comfortable space for visiting and with some flexibility for visits; and, the level of privacy afforded for what can sometimes be quite fraught interactions.
- Carers felt that many of the places where visits took place were overly restrictive and unsatisfactory, even taking into account the need for certain levels of security.
- A key source of stress around visiting was not being consulted or kept informed about their relative. Having staff that were able to support the caring relationship made all the difference.

Conclusions

In considering the issue of carer support from the perspective of both services and carers, this study has attempted to explain the identified discrepancies in service delivery. Examples of good practice in the support of carers were noted throughout the study, and these included investment in information exchange, carer support or development workers, carer support groups and behavioural family therapy. However, a significant finding was that carer support is inconsistent across Scotland and within some units, and secondly that the reasons for low uptake of available support are understood differently by staff and carers. Staff identified carer choice as a main reason for this, whereas carers identified a number of access barriers.

From carers' perspective the most important change that can be made is for staff to perceive carers as important to engage with, with needs of their own, as effective allies in a triangle of care, and relate to them consistently in a welcoming and respectful manner. The increased emphasis in health and social care policy on the importance of supporting and involving carers needs to become widespread practice. The fact that carers can attest to the benefits of such an approach suggests that this is achievable in forensic settings without compromising confidentiality or risk management. While there is good practice, the most pressing issue would seem to be the need to increase the range and spread of support, and to address the current inconsistent and patchy provision of carer support.

This study has a number of limitations including that it adds little to the literature on the separation of forensic patients from their children (Chao and Kuti, 2009), or the experience of diverse forensic carers, especially those from BME groups. It has not specifically explored issues that may be specific to women who require forensic care or the needs of disabled people, but arguably these remain important areas for further research and practice development.

Recommendations

As a minimum, we underline the importance of the following general recommendations from the *Triangle of Care*:

1. Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
2. Staff are 'carer aware' and trained in carer engagement strategies.
3. Policy and practice protocols regarding confidentiality and sharing information are in place.
4. Defined post(s) responsible for carers is/are in place.
5. A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.
6. A range of carer support services is available.

To meet the specialist needs of forensic carers in Scotland, we further recommend:

- Acknowledging and sharing across the forensic estate information about existing good practice in fostering a culture of partnership with carers and supporting them to be a core part of forensic mental health services.
- Having designated staff within forensic mental health services who are responsible for advancing the carer agenda, driving the agenda forward and being a point of contact for new carers.
- Forensic mental health services providing a comprehensive and accessible information pack for carers, taking into account their diverse communication needs.
- Forensic mental health services considering what information, advice and support planning needs to be in place to alleviate uncertainties for carers associated with transitions.
- Forensic mental health services working to minimise the stigma forensic carers experience, and doing so in partnership with carers who have direct experience of this stigma.

- Involving carers in support planning and review processes including active encouragement and support to be involved in CPA reviews.
- Forensic mental health services holding regular carer events such as open days at secure units.
- All forensic mental health services organising and/or supporting a regular forensic carer support group serviced by the unit or in partnership with the voluntary sector or carers along the lines of existing successful forensic carer groups.

What happens next?

Support in Mind Scotland (SiMS) and the Forensic Network will work with carers and staff in the services to produce guidelines for good practice and a way of helping staff measure their effectiveness in involving carers more in the care and treatment of their relatives. The report will also be used to carry out further consultation and discussion amongst carers so that we ensure that carers themselves know about and can refer to the findings.

The full report and plain English summary are available at:
www.supportinmindscotland.org.uk ; www.forensicnetwork.scot.nhs.uk and
www.uclan.ac.uk

Contact for more information

More information about this report and other support available to carers and people with serious mental illness is available from Support in Mind Scotland (SiMS) on 0131 662 4359. Email: info@supportinmindscotland.org.uk

Thank you

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We are particularly grateful to the relatives and families who shared their experiences of carer support with us, with the aim of improving support for all forensic carers in Scotland. We hope this report makes a difference.

The University of Central Lancashire team was led by Dr Julie Ridley and included Dr Mick McKeown, Fiona Jones, Shelley Briggs and Monica Deypurkaystha; and independent researchers Karen Machin, Dr Ann Rosengard, and Simon Little.

For further information about the research contact:

Dr Julie Ridley, School of Social Work, University of Central Lancashire, Harrington Building, Adelphi Street, Preston, PR1 2HE.

Tel: 01772 893402
 Email: jridley1@uclan.ac.uk



**Support in Mind Scotland
6 Newington Business Centre
Dalkeith Road Mews
EDINBURGH EH16 5GA**

**Tel: 0131 662 4359
info@supportinmindscotland.org.uk
www.supportinmindscotland.org.uk**

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