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Family needs and family intervention programmes for psychiatric patients with a forensic background

Key Messages

1. The problems faced by family members of forensic psychiatric patients are serious, multiple, largely unidentified and under-served. Family members have difficulty accessing continuing services, particularly those in the community.
2. Better information, interaction, and discharge planning is required to support the integration of the patient into the community and family life.
3. The media is aggressive and intrusive; more control should be imposed.
4. Coping is made more difficult due to the community stigma perceived by family members and patients.

Introduction

The last three decades of psychiatric research have seen an increasing awareness of the effects a mentally ill family member has on other family members, as most patients live with their families.¹ Many family members report that their caring role is stressful.² Research has demonstrated that the family response to patients is highly correlated with relapse.³ These issues are exacerbated in families caring for a patient who has been involved with criminal offences. Yet very little research has been published examining the specific problems and experiences of such families. Violence and social stigma may further stress the families of forensic psychiatric patients.⁴ These families bear a greater burden than families of non-forensic psychiatric patients.

Aims and objectives

The objectives of this study were to explore the experiences and needs of families of forensic psychiatric patients in Hong Kong, with particular respect to their contact with the police, courts, media, and service providers; and to make suggestions on the development of service provisions useful to them.

Methods

Study design and instrument

This study was conducted from April 1999 to March 2000. As this was the first research conducted on this topic in a Chinese society, an exploratory, qualitative method was adopted. The literature search suggested that the Relative Assessment Interview (RAI), widely used by clinicians and researchers in the field, would be the most suitable for obtaining information regarding the problems and perceived needs of caregivers coping with family members with schizophrenia.⁵ The information from this structured interview was used to guide the family intervention. As the RAI does not address the additional family issues that may occur with offenders with schizophrenia, the section on 'psychiatric history' was deleted and 23 items regarding the forensic nature of the illness and offence history were added. Two independent qualified translators translated this expanded version. Content validity and cultural relevance was established using a panel of 10 psychiatric professionals.

Sample

All 23 interviews were conducted with family members at Castle Peak Hospital. The nursing staff recruited the families. The refusal rate was about 40%. Refusals were mainly due to time pressure or unwillingness to discuss intimate family matters with strangers. Each interview took about 1 hour and was audio taped for transcription and translation into English. An independent specialist confirmed the English and Cantonese transcriptions. The English version was used as the basis for content analysis.

Results

The patients were primarily male (20/23) and most had a previous psychiatric hospital admission (14/23). Nine had a history of physical violence, much of

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which was directed towards family members. The patients were closely related to the visiting relatives (husbands and wives, sons and daughters, brothers and sisters).

Almost all the offences the patients committed involved physical violence (or serious threat of it) to another person (21/23), three of which were indecent assault. The remaining two crimes were child abduction and drug addiction. Fourteen of the victims were related to or known to their assailant. The notion that mentally ill people attack strangers was not supported by this research.

Media, police, and courts

It was expected that the most common stress among relatives of forensic patients would be from the media and legal proceedings. The relatives largely perceived that the treatment of the authorities was reasonable under the circumstances. The greatest level of distress and anger was associated with the grossly intrusive behaviour of the print media. Revelations in the newspapers meant that the violence and/or offence were made known to relatives, workmates, and neighbours—a serious breach of privacy as indicated in the following transcript.

“When the ambulance came [to take him to hospital] two reporters were waiting downstairs. I was naive and didn’t think of covering myself with a blanket. So they took full pictures of me that were in the newspapers the next day. When I arrived at the hospital 6 or 7 reporters were already there to take photos. Then after surgery, when I was wheeled out of the operation theatre, I was tired and the wound ached, but these reporters still followed me for an interview. I was very upset and very unhappy. They even came into my ward at the hospital... All my colleagues knew about it. But I didn’t talk about it and they didn’t ask.”

Concerns about the future

Respondents were asked two questions that pertained to the future: “where would the patient live after discharge?” and “what health and social services would be available and/or useful?” Seven respondents were certain that the patient would live with family members, but another seven were adamant that the patient would not do so. Respondents were concerned about living arrangements because of the patient’s potential for violence and inability to control it, a feeling that was particularly strong among elderly mothers and wives. Most respondents were not knowledgeable about available social services or their use to them. Few had prior experience with social service support and most were unaware of community-based rehabilitation programmes. The relatives had little contact with the hospital staff despite being regular hospital visitors. Although the relatives showed considerable love, care, and concern for their family member, many were content that they remained in hospital where they were safe and did not cause trouble.

The brother of a forensic psychiatric patient said that: *“Because there are not enough beds in hospitals, the doctors very often just shove their responsibility onto patients’ families... if there is someone to take the patient home... the doctors would be very happy. But I have a family. I can’t have my brother to live with me. My mother is over 60. How can the society be so cruel as to let someone over 60 take care of someone so strong... There’s a 70% chance that he will relapse. It’s really quite dreadful.”*

Informal caring network

The notion that the extended family members share the burden of support and care for these patients was not upheld. Only few members of the immediate family were involved in care and they tried hard to refrain from letting others know about the patient’s illness and offence. They assumed that relatives were unhelpful and critical and even discriminatory, and expected that neighbours and workmates would mock, say hurtful things, or gossip. Many of our respondents had experienced stigma and discrimination and even those who had not, lived in expectation of it.

A mother whose son is a forensic psychiatric patient commented:

“No. If I tell others, they will laugh at me. Sometimes when I go out with him, his arms and legs shake and people would call out after him ‘stupid oaf, stupid oaf’.” At this point she began to weep.

“He cares a lot about his ‘face’. Not only does he want to save his ‘face’, I want to save mine, too. Though I don’t feel his illness is a sin, sometimes when we go out, I could see his body trembling. Even I feel uncomfortable, not to say other people. We have become distant from relatives and friends. I don’t want to see them. I don’t go to visit even the closest ones because of my son, so that they won’t come over to visit us. We don’t have anything to chat about. I have a son who is like this, alas. It is not a sin but I feel very downhearted.”

Although they were largely grateful for the care received in hospital, they wished to be more involved and informed about the care and treatment plan for their family members. They were particularly concerned about the discontinuity in medical care.

Discussion

Although the sample size is small and may not be representative of the population, much can be learned from the experiences described by these family members who are underserved and potentially traumatised. The greatest stress comes from the aggressive and intrusive reporting of the media. This causes great distress to the patient and family, as most people do not know how to deal with the

media.

Family members reported that they experienced or expected to encounter stigma and discrimination and therefore went to great lengths to conceal the illness and offence, even from very close relatives. By doing so, they simultaneously cut themselves off from sources of support. The burden of caring for the patient was not shared by extended family members and usually fell to the very close family members and sometimes to a single person only, usually a mother or a wife. Lack of knowledge of or uncertainty about access to community services inhibited families from receiving appropriate aftercare support. There is a lack of coordination between hospital and community-based services. Client-focused coordinated services and a continuity of care model should characterise service provision for these patients.

One outstanding feature of the interviews was just how much violent behaviour family members tolerated over the, usually lengthy, course of the patients' illness. Much of this violence is absorbed by the family and not reported, unless it is very severe. The respondents perceive that it is their job to provide care to patients once they have been

discharged from hospital. Given that psychiatric illness, particularly with forensic involvement, causes a decrease in family productivity, more help and support is needed for those providing care. The situation is further exacerbated by discrimination and social stigmatisation by the community.

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