EVALUATION OF MENTAL HEALTH SERVICES IN THE FREE STATE

PART IV. FAMILY BURDEN AND PERSPECTIVES

Melvyn Freeman, Tennyson Lee, William Vivian

Objective. To assess the burden of community psychiatric care on family members. The attitudes of family members, the level of support they receive from the health service and their care preferences are described.

Design, setting and subjects. Semi-structured interviews were conducted with 62 family members of patients attending clinics and 24 family members of patients who had 'defaulted' from the service.

Results. Most family members appear to accept having the psychiatric patient staying with them in the community. For many the burden is clearly substantial, both socially and financially. While black families appear to be most burdened, services favour white families. The extent of the burden is illustrated by the fact that 27 black (56%) and 4 white (31%) family members wanted inpatient rather than community care and 42 black (86%) and 10 white (77%) family members wanted day care for their family member.

Conclusion. There is a need for intervention in order to address the considerable burden placed on the families of psychiatric patients before deinstitutionalisation occurs on a large scale.

Internationally, caring relatives have been found to experience significant difficulties. These can broadly be categorised into ‘subjective’ and ‘objective’ burdens; that is, experiential difficulties and personal perceptions on the one hand, and concrete difficulties and constraints on the other.

Issues that have commonly been found to be problematic for families include effects on relationships, both within the family and with regard to the community, and financial difficulties, including expenditure on the relative’s behalf, and loss of earning opportunities.

In the Free State the vast majority of patients attending psychiatric services as well as those who had defaulted from the service lived with relatives (see Part III). This study outlines the experiences of these family members. While the need for consistent and carefully organised support from caregivers is a recurrent theme in the literature on deinstitutionalisation, the burden on caregivers and their perception of support has generally not received much attention as an evaluative tool in examining community care alternatives; certainly no study could be found for a developing country. In this study family burden was considered an essential measure of the success of the programme.

The objectives of this study were to assess the burden of community psychiatric care on family members, the level of support they receive from the health service and their care preferences.

METHOD

Subjects

A convenience sample of 62 family members accompanying patients attending clinics for psychiatric care were interviewed. Approximately 4 family members were interviewed in each of the 16 clinics included in this study (see Part I). Forty-nine black and 13 white family members were selected.

In addition, a convenience sample of 22 (16 black and 6 white) family members of patients who had defaulted from the service were traced and interviewed. All patients who had defaulted from the service were identified (see Part III) and family members were chosen for follow-up. Family members were contacted by telephone or physical address. If a family member could not be reached or refused to be interviewed, the next subject was traced.

Research instrument

As no appropriate validated interview schedule was available, an instrument was designed and piloted specifically for this evaluation. The interview schedule consisted of 34 questions and was conducted in the patient’s language of choice, i.e. English, Afrikaans or Southern Sotho.
Analyses consisted of chi-square tests, or Fisher's exact tests (when any expected value in a cell was less than 5). Statistical significance was accepted at $P < 0.05$.

RESULTS

A high percentage of patients lived with immediate family members — 42 black (86%) and 10 white (79%) attenders and 13 (69%) and 5 (66%) defaulters, respectively.

Family burden — attending patients

In response to an open-ended question regarding burden of the patient to the family, 21 black (43%) and only 2 white (15%) family members of attending patients reported feeling burdened. However, a number of family members who answered in the negative to the open-ended question gave affirmative answers to prompts indicative of burden. Both subjective and objective burden was experienced.

Table I indicates that psychiatric patients in the community place notable strain on their families. Black families were more affected than white families, although not to statistically significant levels. However despite this burden, 39 black (79%) and 9 white (69%) family members said that they were happy to have the patient continue staying with them.

Financial burden

The financial burden that psychiatric patients put on families is tempered in part by the fact that a number of patients receive disability grants (34 black (69%) and 7 white (54%) patients in the patient attender family sample). Nonetheless 16 black (33%) and 2 white (15%) family members complained about the financial burden of having to support a psychiatric patient. Of the 33 subjects (53%) who responded to a question regarding whether a family member had given up employment in order to look after the patient, 10 black (40%) and 1 white (12%) family members answered in the affirmative.

Support from and perceptions of the health services

Almost all family members of attending patients felt that the clinic helped the patient (96%). However, 4 (7%) said they were dissatisfied with the treatment received by their family member. Support received by families was uneven and there were substantial racial differences in the level of service offered (see Table II).

Table I. Relationship between patients and family or community

<table>
<thead>
<tr>
<th>Attenders</th>
<th>Defaulters</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td>White</td>
</tr>
<tr>
<td>(N = 49)</td>
<td>(N = 13)</td>
</tr>
<tr>
<td>Violence with another family member</td>
<td>13</td>
</tr>
<tr>
<td>Poor relationship between family member and patient</td>
<td>10</td>
</tr>
<tr>
<td>Patient disrupted family relationships</td>
<td>20</td>
</tr>
<tr>
<td>Illness changed relationships in family</td>
<td>20</td>
</tr>
<tr>
<td>Friends/family stopped visiting/visited less frequently</td>
<td>22</td>
</tr>
</tbody>
</table>

Financial burden

Services offered to white families were generally more extensive than those offered to black families, with the provision of health information statistically significantly higher for white families. The emphasis that the Free State model puts on the family approach to care is better reflected in white than black patient community care.

Responses to alternative forms of care

A measure of the perceived burden and need for support is family preference for institutional over community care alternatives. Twenty-two black (47%) and 3 white (23%) families said that if given the choice they would prefer to have the patient in hospital in central Bloemfontein. This increased to 27 (56%) and 4 (31%) respectively if the inpatient care could be provided in their nearest town. Reasons why families (all races) wanted patients in hospital included the patient being insufficiently well to be at home (23 (37%)), and that the patient and family could not cope at home (8 (13%)). Need for support is also indicated by the fact that 42 black (86%) and 10 white (77%) family members attending patients reported that they would want their family member to attend day care either on a permanent or temporary basis.

Family burden — defaulting patients

The burden on families of patients who had defaulted from the service was not significantly different from that of families of patients who continued to attend the service. Differences
between families of attending and defaulting patients were not statistically significant even with regard to wanting inpatient hospital or day care for their family member.

Nonetheless the fact that 14 black (89%) and 2 white (50%) family members attempted to persuade their family member to return to care when they realised that treatment had ceased suggests that the psychiatric service is perceived to be useful by families. Fifteen family members (65%) perceived differences in the patient’s functioning after they had defaulted from the service.

**DISCUSSION**

The number of family members caring for psychiatric patients in the Free State is high. For example, 84% of patients attending clinics and 68% of defaulters in this study lived with family members, compared with 59% of patients discharged from hospital care in Harrow in the UK.!

Lack of available supervised accommodation in the Free State (compared with Harrow) and greater community orientation in traditional African communities, are thought to largely account for this difference. The result, however, is that the burden of caring for psychiatric patients is likely to impact more on families in the Free State (and other less resourced communities).

Remarkably, most families, especially black families, appeared to accept having a patient stay with them. Despite a number of family members having had to leave employment, and explicit changes in many family and social relationships, only a few family members said that they were unhappy about having the patient stay with them. The fact that 66% of the patients interviewed received disability grants (in a largely impoverished area, certainly for most black people) may have had an important bearing on this finding, as whole families survive on such grants. Moreover, the ‘acceptance’ may be rather superficial. In certain instances, the process of care is perceived as occupying the family system, as well as the tendency towards acquiescence in an interview, likely resulting in many family members expressing their consent to caring for the patient. The facts that 53% of respondents said that they would prefer to have their family member in long-stay hospital care, and that 83% of family members wanted day care, may be a more valid indication of the burden being experienced. The high number of family members preferring hospital care to a community alternative is in stark contrast with the finding in Harrow, where only 1% of family members wanted the patient to be hospitalised in preference to receiving community care.!

**LIMITATIONS OF THE STUDY**

A limitation of using family burden and support as a mechanism for evaluating the success of a community mental health programme is that there is no objective benchmark regarding whether the extent of the burden is within acceptable limits or not. Moreover, while the subjective evaluation of the caregiver is an important measure, responses are highly dependent on expectations. People who have traditionally received superior services are more likely to expect better care than people whose care has been poor in the past. If services were to be provided in response to expressed need (from either patients or their family members) it is possible that comprehensive care would be provided to those causing little objective community upheaval and who may indeed have the most community services available, rather than to people in greater objective need.

Only family members accompanying patients to the clinic (with regard to attenders’ families) were interviewed. This research may, therefore, be biased towards family members who showed special interest in the patient or perhaps towards family members of patients who need special attention, i.e. needed to be accommodated to the clinic.

Few differences were found between family members of patients attending clinics and those who had defaulted from the service. This relates perhaps to the fact that social functioning was similar between attending and defaulting patients (see Part III).

Despite its limitations, the study shows clearly that for a considerable number of families, caring for a psychiatric patient in the community is burdensome and little support is available to them. The burden is worse for black than for white patients, while support from the health service favours white families. There is a need to pay attention to this burden before deinstitutionalisation occurs on a large scale. Experience elsewhere is that there is need for a wide range of facilities in the community in order to sustain chronic psychiatric patients.!

For full acknowledgements, see Part I.

**References**


Accepted 19 July 1998.