

## Long-term Psychiatric Patients in the Community

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The reduction of mental hospital populations in Britain and the United States has generated a considerable amount of literature on policy, but detailed studies of the effects on patients and the conditions under which they live after discharge are rare. In the United States, a National Institute of Mental Health review of the literature commented that “the question of what actually happens to patients who leave mental hospitals and re-enter the community is largely unanswered” (Bachrach, 1976).

In Britain, there have been three main research approaches:

- (a) computerised case-register studies based on the Camberwell model (Wing & Hailey, 1972), of which Cheadle *et al* (1978), Howat & Kontny (1982) and Sturt (1984) are recent examples
- (b) studies of patient groups from particular agencies, such as day hospitals (Milne, 1984), assessment units (Eagles & Gilleard, 1984), district general hospital units (Gibbons *et al*, 1984) or ward support schemes (Mitchell & Birley, 1983)
- (c) studies of the input of specific professional groups, such as general practitioners (GPs) (Shepherd, 1976), social workers (Fisher *et al*, 1984), or community psychiatric nurses (Paykel *et al*, 1982).

All three types of study are service-based. They provide a valuable approach to the evaluation of services, but give only limited information on what the patients in the ill-defined area called ‘the community’ actually experience. Some patients may be receiving a complex of services from different agencies, while others receive few or no services. Detailed tracer studies which take the patient rather than the service as a focus are needed. Who helps? Who fails to help? How do hospital-based and GP services fit together with social work, private, and informal (family care) services? The move from hospital-based to community-based services involves a sizeable re-

definition of patients’ problems from ‘medical’ to ‘social’. Does it work in practice?

Studies involving interviewing ex-patients and their relatives or other carers are difficult, and therefore rare. Patients move, and are sometimes difficult to trace, so there is a risk of attrition in the sample. Some prefer to forget their time in hospital, and do not wish to be interviewed; some, in continuing distress or confusion, may misunderstand the purpose of the exercise, and require sensitive handling; and some may not give coherent replies. The study of non-medical services is new to most medical research workers. The few recent and relevant follow-up studies (McCreadie, 1982; Sadavoy & Reiman-Sheldon, 1983; Johnstone *et al*, 1984) have all been concerned with symptomatology rather than with the quality or mix of care. An opportunity to carry out a study for York Health District on patients discharged from the three York mental hospitals (Clifton, Naburn, and Bootham Park) into the York area was therefore welcomed as a pilot project. A full report on this project is available (Jones, 1985).

The two samples chosen for the follow-up consisted of:

- (a) the long-stay group: all patients who had been continuously in hospital for over one year, and who were discharged in the period 1 April 1982 to 31 March 1984 ( $n = 50$ )
- (b) the elderly confused group: 100 patients selected randomly from a total of 203 aged 65 and over with a diagnosis of senile dementia (ICD categories 290.0–290.9, World Health Organization, 1978) and discharged during the same period.

Perhaps the most important finding is that the project was viable. All but two of the patients (elderly confused who had left the district) were traced, and no major objections to the research procedure were encountered. The project was approved by the local Medical Ethical Committee. In all cases, the Responsible Medical Officer agreed to the follow-up.

Patients' general practitioners were consulted, and in only four cases did they think that an interview would be too stressful for the patient: these cases were removed from the sample. The interviewers (two senior social workers, two college lecturers, and a psychologist) were instructed to withdraw at once if either patients or their carers had any objection to the interview procedure: this occurred in only 12 cases. Most were happy to talk, and many seemed to find a friendly visit helpful. The only complaint came from an ex-patient who had *not* been included in the sample.

In-depth interviews, based on checklists, lasted from one to three hours. The interviewers completed both the checklist and a detailed case study for each patient. The case studies produced a wealth of data from which it would be possible to derive a substantially refined research instrument for future studies, with an improved computer database.

## Results

### The long-stay sample

Patients interviewed were evenly divided between men and women, and covered a wide age-range – from 24 to 82. The length of stay in hospital varied from just over a year to 43 years. Over half had a diagnosis of schizophrenia. The older patients tended to have one admission and a long hospital stay, while the younger ones had multiple admissions and shorter stays. At the time of interview, only five were living in their own homes or a family home. The rest were scattered between local authority homes or hostels, private registered homes, group flats, and lodgings. None were in prison; one was sleeping rough, and two were back in mental hospital. Placements had been made with great care (York has a homefinder who believes in 'intuitive matching' between the patient and the setting – a highly individual process) and most patients appeared to have made a reasonable adjustment.

### The elderly confused sample

Of this group of 100, 35 had died before the time of interview, and 23 were back in hospital. Three of these patients had been discharged in their nineties. Only ten of the sample were found to be living in their own homes or a family home. Others had been discharged to local authority or private registered homes, or to sheltered housing. The elderly confused in their own homes were much less well-supported than the younger long-stay patients. Where there was only a mild degree of senile dementia, the family was

large enough to spread the burden of care, and there was enough money to cushion the situation, the problems were manageable; but where the mental condition was severe and disruptive, there were physical complications such as blindness or incontinence, the burden of care fell exclusively on one relative (usually a husband or wife, also old and often in failing health), and the financial resources were strained, the situation could be nearly intolerable. Neighbours offered little help, and friends were scarce. Although the health and social services were initially involved, visits tended to tail off after a few months. The expectation of the current model of community care is that patients will improve after discharge from hospital; senile dementia does not fit the pattern.

### Hospital discharge plans

These were faithfully drawn up, but tended to be unrealistic. They made no mention of where the patient was expected to live (presumably on the assumption that they would all return to their own homes). They did not list GP or out-patient clinic services, and there was a marked under-use of social services. Most discharge plans recommended the use of only one community-based service, although patients in fact needed several in combination. The situation after discharge was often unstable, and the need for support more complex than the discharge plan data suggested. We concluded that what was needed was not a 'discharge plan' (which clears a hospital bed), but a community care plan which offers a possibility of stable living conditions with adequate support.

### Success of placement

The patients in these samples did not bear out the gloomier prognostications of those who distrust care in the community – similar surveys in other areas might have less positive results. Of the total of 38 who died before the interviews took place, 35 died of natural causes (two elderly confused patients died as a result of falls, one in hospital and one in a home, and one long-stay patient committed suicide). But were the rest happier in or out of hospital? It is often taken as axiomatic that any kind of life 'in the community' is better than staying in a mental hospital; as the survey results indicate, however, patients go out to a variety of settings, and not all of them are necessarily beneficial.

### Quality of life study

The research team attempted to devise a scale

sufficiently flexible to cover both life in hospital and life in the variety of settings to which patients were discharged, and the matching of conditions for each patient in both settings. While many quality-of-life scales have been constructed for different purposes, the combination of hard and soft data poses severe problems of measurement, and there are difficulties in weighing individual items. Scales based on some concept of 'normal living in the community' are open to the objection that we have little idea what is 'normal' for severely handicapped or disturbed people. After studying existing scales, the team came to the conclusion that the construction of a new and simplified scale was the only useful approach. The York Scale is based on Maslow's (1943) hierarchy of human needs. It measures four groups of needs (survival, safety/security, purpose, and independence) on three dimensions: needs met, needs partly met, and needs unmet. The scale needs further development, but it was found that

- (a) patients' own homes scored well on choice and autonomy, but not on health care, personal care, activities, and companionship
- (b) local authority homes provided personal care, but scored poorly on health care, privacy, and activities
- (c) private homes (usually run by psychiatric nurses) provided good personal and health care and activities, but were often cramped and lacking in facilities
- (d) mental hospital wards provided best for basic survival needs, health care, and activities, but not for personal choice, privacy, or autonomy. Nor did they provide for stability, since patients might be moved to another ward or discharged at any time.

### Conclusions

The findings of the survey should be treated with caution, since the samples were restricted in scope and comparatively small. However, they provide pointers for practice and for future research.

Most of these patients were still living in fairly institutional surroundings. Whether they were better or worse off than in hospital depends on a variety of factors relating to the individual patient and the individual setting – there is no clear general answer indicating the superiority of 'hospital care' or 'community care'.

The questionnaire had been constructed in the expectation that most of the patients in the samples would be found in their own homes, and that if they

were fit for discharge, they would be able to sustain an interview. Both of these assumptions were disproved. Only one in ten of the patients were in their own homes, and few were capable of answering questions. Most of the information came from people such as relatives, officers in charge of homes, landlords, hostel wardens, and hospital staff. Often even professional staff were uncertain in their replies – they could not remember the names of GPs, or say when a visitor had last called, or whether patients had relatives. Patients who are incoherent, or passive and undemanding, do not seem to inspire good record-keeping, although they may need it more than most.

Even in York, a fairly compact city, the study revealed the great complexity of care in the community: the difficulties which health and social services have in working together when they have different legislative bases, different working styles, different patient groupings, different planning and budgeting cycles, and different professional backgrounds; the problems of the small voluntary societies in trying to work with the statutory 'giants'; the isolated pockets of private care, and the difficulties of co-ordinating all these services with GP care. The 90 patients interviewed – all living within a limited area – had 67 different GPs. Repeated official exhortations to collaboration and co-operation (Department of Health and Social Security, 1975, 1978, 1981) will be of little effect unless attention is given to finding administrative solutions which provide a mix of services where needed.

Modest research projects of this kind, which can be of practical and immediate use to the psychiatric services, may be of particular value when a major policy shift is being implemented. They need to be tightly scheduled, and to provide quick returns. The survey reported here was planned, executed, and reported back to York Health District within twelve months. It took place in the context of rapidly-developing services; in the past year, two additional consultant posts have been established, with specific responsibilities to develop after-care services for younger patients with chronic handicaps, and for the elderly confused; numbers of community psychiatric nurses have been increased; an 'at risk' register has been set up; funds have been released to social services to provide for collaboratively planned day care; community mental health teams are being formed to work with GPs in designated localities; and plans are well ahead for the provision of four community resource centres and eight community units for the elderly. Small-scale in-depth research can help to maintain the momentum of change, and provide rapid feedback on groups in special need.

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