

Observations from community care for serious mental illness during a controlled study

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A controlled study of community care in serious mental illness (SMI) was carried out. Patients with SMI were randomised to have hospital care or be looked after by a community psychiatric care team in a Daily Living Programme (DLP). The day-to-day work of a clinical team with the difficulties encountered in delivering community psychiatric care in an inner city is described. There were seven deaths from self-harm during the 45-month study. One DLP patient committed homicide. An ordeal by media following this and the suicides are described. Lessons learnt include the need for the community care team to be responsible for discharge from any in-patient phases and for attention to team morale, especially during adversity, and to time spent working under pressure.

In recent decades there has been worldwide concern on what the exact function is of a hospital psychiatric bed in mental health care, especially for those with serious mental illness (SMI). Many countries have run down and closed large mental hospitals and resettled their former patients in more natural settings, most of whom do not wish to return to large mental hospitals. Many disengage from psychiatric care.

The care of SMI (usually schizophrenia, severe depression, and mania) has often been studied in settings alternative to that of in-patient care. Randomised controlled trials have compared community with in-patient care (e.g. Burns *et al.*, 1993) and controlled contrasts have been made of day v. in-patient care (Creed *et al.*, 1990), and of community emergency service v. hospital care (Merson *et al.*, 1992).

Conclusions from controlled studies (reviewed by Marks & Scott, 1990) and from uncontrolled ones were consistent. They found that in-patient care nowhere outperformed good alternatives, e.g. in Madison and in Sydney. It also cost slightly less – between 4 and 25%.

A model of care for SMI emerged, sharing elements with those for other chronic conditions like diabetes. People with SMI require not long-term in-patient care but a daily support network

to offset their chronic deficits and deal with crises. A comprehensive service should include 24-hour access for crisis resolution, out-patient clinics, day care, some long- and short-term in-patient facilities, and specialised living and work arrangements. SMI patients require continuing support and regular contacts concerning housing, work, finance, socialising, hygiene, physical health and medication. Determined follow-up is essential to prevent relapse of disengaging patients.

A Daily Living Programme (DLP) of activities is needed for a more satisfactory existence. Individual problems have to be delineated and dealt with. The outcome of the first European randomised controlled comparison of DLP care with standard hospital care over 45 months was described elsewhere (Audini *et al.*, 1994; Knapp *et al.*, 1994; Marks *et al.*, 1994). The present paper outlines the DLP's clinical practice with 92 out of the 189 SMI patients randomised to home-based DLP care in the controlled study.

The study

In 1986 the Department of Health and Social Security (DHSS) invited bids for funds of up to £400 000 per region for innovations in community psychiatric care. Such a bid was made from the Bethlem-Maudsley Hospital to try to replicate the earlier randomised controlled studies in the USA and Australia, conducted in very different settings from the inner-London catchment area of South Southwark (population 136 000) – the eighth most deprived borough in Britain.

The bid attracted not £400 000 but an award of £272 000. The project therefore had to be resource-driven, not needs-driven. This posed the problem – how many staff and of what disciplines could be employed to cover which hours of the working week? This, for a seven-day service, turned out to be one psychiatrist

(senior registrar, first MM, then RL and then Dr Vik Watts), seven psychiatric nurses (managed by GM), a social worker for 14 months, and a secretary/coordinator. One nursing post was occupied by a senior occupational therapist in the second and third years of the project. A consultant psychiatrist (JC) altered his working week to devote two sessions to head the Daily Living Programme team (DLP).

The hours that could be covered by the staff funded were initially 8.30 a.m. to 9 p.m., Monday to Friday, and 9 a.m. to 5 p.m., Saturdays and Sundays. Every night a team member was on-call by telephone for advice, with the ever-open Emergency Clinic for problems which could not be contained at home. In the original DLP study patients had home-based care for a mean 20 months after intake. Subsequently a randomised half of those DLP patients continued in DLP care for a mean of a further 27 months (the other half went into standard hospital-based care). Five and a quarter years elapsed from intake of the first patient in October 1987 to closure of the DLP in December 1992.

At entry all 189 patients were judged to have SMI, lived in South Southwark (or had credible associations with it, if for example, they were of no fixed abode), were aged 17 to 64, and had no acute or chronic brain syndrome or primary addiction. A decision had been made independently (in almost all at the Emergency Clinic) that admission was necessary. They were randomised to be admitted for standard hospital-based care ($n=97$, controls) or to be looked after by the DLP team ($n=92$) caring for people mostly in their own homes.

Randomisation was stratified according to whether patients were would-be first admissions (which, it was thought, might have a good prognosis with any treatment – this turned out not to be the case) or readmissions. Half of all would-be first admissions were randomised to DLP care. However, only 20% of SMI patients who had had previous admissions were randomised to DLP care, to avoid swamping the DLP service and to take account of the rest of the hospital's needs. Both cohorts had an independent evaluation funded from the Department of Health (the then DHSS) (Muljen & *et al.*, 1992a, 1992b). The subsequent withdrawal phase was described elsewhere (Audini *et al.*, 1994; Marks, 1995).

The work of the DLP team

None of the team, except the consultant psychiatrist and the senior registrar, had previously worked in the community. After a short induction period the DLP began to take on the new patients

who had been randomised to its care and started to learn on the job. The care was problem-centred. A key worker of whatever discipline worked out with the patient what the chief problems were and goals to deal with them, and agreed statements to describe them.

A problem, rated 0–8 on severity, might be: "Repeated discontinuation of neuroleptic medication with recurrence within weeks of delusions and auditory hallucinations".

A goal, rated 0–8 on difficulty of achievement, might be: "To accept depot injection of 40 mg of flupenthixol intramuscularly every two weeks for six months in the first instance".

The therapeutic input was measured under the headings: face-to-face contact with patient, telephone time, travelling time, and face-to-face contact with others. This was to allow the direct therapeutic input (and so cost) to be calculated for each patient. Indirect costs were also measured (Knapp *et al.*, 1994).

After extensive experience the team described the DLP's operations in 38 points.

The DLP *provides* for its patients:

- Monitoring of clinical and social state
- Timely involvement of other relevant agencies and persons
- Relationships with team members to help lessen disability
- Easy access
- Close attention to and an understanding of their experience, behaviour, strengths, weaknesses and life settings
- Admission to hospital, continuing contact and planning
- Forward thinking
- Occasional meals, clothing, furniture and loans
- Sometimes an unshared goal, e.g. detention under the Mental Health Act
- Counselling
- Models of understanding of their own predicament.

The DLP *advocates* for its patients with:

- Police, lawyers, courts, prison officials as appropriate
- Public utilities over arrears and continuing supply
- Social security officials for entitled benefits
- Housing departments & associations, hotels and hostels, relatives, friends and landlords for housing needs, arrears and future payments
- General practitioners, hospital staff and social services
- Employers
- Shops and café workers

Voluntary organisations and clergy
Local authorities over taxes, bus passes, etc
Neighbours, relatives and friends.

The DLP *prompts* its patients:

Towards better nutrition, hygiene, physical health and budgeting to attend important meetings.

The DLP *persuades* its patients, if at all possible, to:

Accept therapeutic interventions judged as best serving patients' interests
Decreasing mind-altering substance abuse.

The DLP *negotiates* with its patients on:

Contacts
Problems and targets
Means to solve problems and achieve targets.

The DLP *measures* in its patients at entry into care, during it and on discharge from it:

Salient problems and their severity
Difficulty in achieving the negotiated targets
Team time input face-to-face, travelling, on phone.

The DLP *ensures* that:

It acts professionally always
Its records help the evaluation of its work and could be creditably scrutinised by the courts
Medication is delivered and monitored
Its staff works with an awareness of personal safety
It communicates its working and results to interested others
It does not burn-out and looks for professional development and wider clinical experience
It fosters good relationships within the team and with others crucial to its remit.

Findings

The main findings were that compared to controls:

- (a) the duration (but not number) of admissions for DLP patients fell by 80%, but only as long as the DLP team was in charge of any in-patient phase
- (b) DLP patients became marginally superior on clinical and social scales late at month

- 20, but not thereafter and most remained unemployed
- (c) DLP patients and their relatives were more satisfied with care from month 11 to month 45
- (d) DLP care cost somewhat less
- (e) DLP care did not reduce the number of deaths.

Not everything went smoothly. While visiting a patient a DLP team member was attacked with a carving knife and another was mugged in broad daylight on a main road. Two DLP team members had to barricade themselves in the team's office to prevent a psychotic patient from attacking them.

In the 20 months after trial entry, of the 92 DLP patients, one murdered a neighbour's child and three died from self-harm. During this time there were two deaths from self-harm among the 97 controls. In the next 2½ years one patient committed suicide shortly after passing from DLP to control care, and one of the original controls committed suicide at four years post-entry.

Comment

Novelty tends to attract attention

Fourteen months after the murder and two years after the DLP study had begun, a reporter on a national tabloid newspaper telephoned about the tragedies. She was well-informed. Extensive media coverage followed. It was not laudatory. An MP asked the House of Commons when the government would stop funding its experiment in human lives. In the main evening TV news, questions faced included "Don't you think that with this number of tragedies this way of looking after patients has been discredited?" The fact that at the time there was not even a trend in differences between the groups carried little conviction with the general public.

Alarmed by the publicity, the Ethical Committee (Research) of the Hospital and Institute of Psychiatry which had approved the study ordered an enquiry. This was carried out by a director of nursing services and a consultant psychiatrist unconnected to the DLP, with a lay chairman who was a member of the health authority. The enquiry exonerated the DLP from all blame and ethical approval was continued.

During the same 27 months that the DLP had been working it emerged that there had been 18 suicides quite outside the study among patients who were in-patients of the hospital at the time or had been recently discharged. This high suicide rate had not been previously realised. Questions are not asked as incisively of established methods of treatment, however unsatisfactory, compared

with those asked of a novel form of treatment. All suicides in the Joint Hospital are now subjected to audit.

A natural experiment

After its enquiry, the Ethical Committee (Research) stipulated that any DLP patients who were admitted should be cared for by the ward medical as well as nursing teams. (Previous nursing care had been provided by the ward but most of the medical input and problem-centred nursing care had come from the DLP). After this ruling that the ward team control the length of stays their durations trebled. If time in hospital is to be lessened and patients returned early to care within their own homes, the team caring for them at home must be able to influence the duration of admission.

The randomised withdrawal phase

To give it credit, the confidence of the Department of Health was not shaken by these events. The funding of the DLP should have ended after three years. However, in Madison, Wisconsin, discontinuation of DLP-type care (titled the 'Training in Community Living') had led to the disappearance of all gains by 14 months. The Department part-funded a design in which a half of the initially randomised DLP cohort was further randomised to its continuing care and half returned to standard hospital care. The DLP team was slimmed in line with its new responsibilities. Morale fell, however, after the hospital enquiry and with future funding uncertain. The emphasis on the problem-oriented mode of DLP care diminished and the DLP team was not allowed responsibility for any in-patient phase. Only two of the entire DLP team (JC and Ian Moran) stayed with it throughout its 5½ years.

Independent evaluation of the withdrawal phase from months 30–45 after trial entry was completed on funding from the Wolfson Foundation (Audini *et al.*, 1994; Marks, 1995). The clinical gains of DLP v. control care attenuated and the number of in-patient bed days used rose to that of controls (which fell compared to that in the earlier phase). Patient and relative satisfaction, however, continued to be significantly greater than in the control group.

Conclusion

Only until 20 months post-trial entry for SMI was it possible to reduce in-patient bed use by a motivated team giving home-based care which was preferred by patients and their relatives. At

no time was it outperformed by standard hospital care. Critical media attention can be expected if there are tragedies. Tragedies are likely because SMI patients, whether admitted or in community care, are often dangerous to themselves and to others. The fall in clinical gains after month 20 (in spite of patients' and relatives' continuing preferences) showed that, if maximum gains are to be sustained indefinitely, more careful nurturing of home-based care than we managed is necessary. The home-based team needs to be responsible for crisis in-patient admissions needed by their patients.

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