

BRITISH JOURNAL OF PSYCHIATRY

27.7.1993

DAILY LIVING PROGRAMME

MAUDSLEY HOSPITAL

1. *Staphylococcus aureus*

2. *Staphylococcus aureus*

3. *Staphylococcus aureus*

4. *Staphylococcus aureus*



For 25 years the care of serious mental illness (SMI, which usually denotes schizophrenia, severe depression, and mania) has been studied in non-inpatient settings. Randomised controlled trials compared community with inpatient care in: the USA in Denver (Langsley et al 1971, Polak & Kirby 1976, Polak et al 1979), Louisville (Pasamanick et al 1967), and Madison (Stein 1982, Stein & Ganser 1983, Stein et al 1980, Test 1990); Canada in Montreal (Fenton et al 1979, 1982, 1982a); Australia in Sydney (Hoult et al 1983 & 1984, Hoult 1990, Reynolds & Hoult 1984), and India in Bangalore (Pai & Kapur 1982). In the UK aspects of community care have been studied (Grad & Sainsbury 1968; Johnstone et al 1981; Knapp et al 1992; Lawrence 1991, Lawrence et al 1988 & 1991; Leff 1991 & TAPS 1990; Scott 1980) and controlled contrasts made of day vs inpatient care (Creed et al 1990, Dick et al 1985), standard vs home-based care (Burns et al 1993, Dean & Gadd 1990), and a community emergency service vs hospital care (Merson et al 1992).

In the controlled studies (reviewed by Fenton et al 1982, Holloway 1985, Hoult et al 1983, Kiesler 1982, Marks & Scott 1990, Muijen 1991) and the uncontrolled ones alternatives to inpatient care yielded similar or slightly better outcomes. The most extensive trials were in Madison and Sydney. Compared with standard inpatient care, good community care (CC) yielded similar or superior clinical outcomes. It reduced SMI symptoms at least as much, improved daily role function more quickly, reduced or did not increase the burden on other people, and was preferred by patients. CC outside hospital cost slightly less than inpatient care.

CC, however, did not cure SMI (Leff 1991, Marks 1992, TAPS 1990, Thornicroft et al 1991). Long-term support had to continue. When it was withdrawn gains were steadily lost over 14 months (Test 1990). Patients still needed help with persisting disabilities and handicaps and to be tided over exacerbations even if they became able to live outside hospital and consumed

slightly fewer health care resources. Despite gains many continued to be anxious, depressed and inactive. Only a minority held paid jobs, lived with relatives, and needed no medication. The cost savings were not huge - 4-25%. Unexpected suicides still occurred (Cohen et al 1990). Antisocial activity did not disappear.

The above research led to a model of care for SMI sharing elements with that for other chronic conditions like diabetes or rheumatoid arthritis. SMI patients require not long-term inpatient care but long-term support to reduce chronic deficits and deal with the crises that punctuate their lives.

A comprehensive service for SMI includes 24-hour access for crisis resolution, outpatient clinics, day care, long- and short-term facilities, special living and work arrangements, and ongoing support and regular contact in their homes. Programs must be tailored to individual needs for housing, work, finance, socialising, physical health, hygiene and medication. Skills seldom generalise and so require teaching where required - at home, at work, local shops. Determined followup of disengaging patients is essential.

The above model is a daily living program (dlp) of activities to improve quality of life. It is problem-oriented. This paper describes the outcome over 20 months of the first European randomised controlled comparison in SMI of such dlp care with control standard hospital care (for preliminary results see Muijen et al 1992 a & b). The 3-year study tried to replicate the Madison and Sydney studies in 189 SMI patients in the UK's different health care system in a deprived inner city area.

METHOD

Design

Patients entered the study during its initial 26 months and remained in it for 18 or more months after entry. From Oct 1987 to Dec 1989, 189 patients with SMI from the Bethlem-Maudsley (BM) Hospital catchment area of South

Southwark who were facing emergency admission were randomised to home-based community care (Daily Living Program, dlp) or to control standard inpatient-followed-by-outpatient care. That such admission was necessary was decided by an independent psychiatrist in the BM's 24-hour Emergency Clinic (EC) in all but 3 patients who entered after a domiciliary visit by a consultant.

For patients already under a BM consultant's care, (s)he was asked permission to randomise them. Two consultants declined this. Their few patients resembled those of the other 17 consultants who gave permission.

Before trial entry patients and relatives were asked if they agreed with either home or inpatient care, home care not necessarily excluding admission but minimising it. The BM Ethical Committee and the Department of Health agreed that informed consent to randomisation was unnecessary since home care had been at least as good as standard in/outpatient care in previous studies. Selection criteria: Both new and 'old' patients were included as so many inpatients tend to be readmissions. Patients had to:

1) have SMI requiring urgent hospital admission, including patients who were violent, suicidal, or detained under a Section of the Mental Health Act (1983); 2) be aged 17-64; 3) have no primary addiction (dual diagnoses were accepted); 4) have no acute or chronic organic brain syndrome; 5) be not pregnant at the time of randomisation; 6) be living in, or connected to, the BM catchment area of South Southwark (if of no fixed abode have local family ties or be attending local statutory services).

Randomisation This occurred once the independent psychiatrist decided an emergency admission was needed. Randomisation was of i) all SMI patients facing their first admission (new patients) and ii) 20% of all SMI patients facing readmission after a previous psychiatric admission ('old' patients). The dlp and the control conditions thus each contained half of most new, and 10% of most 'old', catchment area patients facing emergency admission.

TREATMENT

Home-based care (daily living program - dlp)

To allow replication of the Madison approach, members of the Maudsley and the Madison CC teams, and to some extent the Maudsley and Sydney teams, made 10 exchange visits. A one-week staff induction preceded the first intake of patients. The dlp helped SMI patients facing urgent admission to function at home with minimum inpatient care and continued 'assertive outreach' as long as needed. A balance was struck between the risks of neglect and of overdependence. Care type and intensity was tailored to each patient's needs.

It met NIMH guidelines for community support programs (Turner & Tenhoo 1978):

- 1) 24-hour care, 7 days a week, including telephone cover at night, backed by access to the ever-open walk-in Emergency Clinic (EC).
- 2) Treatment at the site of breakdown as soon as it happened. Patients were not strenuously kept out of hospital at all costs, being admitted briefly if warranted. Most dlp care was given at home, even though most patients were admitted for a few days when in crisis, usually at study entry. The dlp cared for them even as inpatients and decided when to discharge to continued dlp care at home, visited patients at home regularly and encouraged them to take medication. The dlp team liaised with relatives, friends, neighbours, landlords, housing authorities, social services, public utilities, employers, police, lawyers, courts, prison officials, and statutory and voluntary organisations. In a crisis visits might be several times daily and last for hours, dropping to once a week or less as improvement occurred.
- 3) Case management: A dlp keyworker (psychiatrist, nurse, occupational therapist or social worker) organised care including health service and local authority resources but did not necessarily carry out all interventions.
- 4) Problem-oriented care: Each patient's problems were formulated, with the patient where possible, as brief statements e.g. 'stops neuroleptics with

recurrence of delusions and voices'. A care plan was devised that set goals to deal with each problem e.g. 'to accept 2-weekly intramuscular injections of 40mgs of depot flupenthixol for 6 months'.

5) Help to maintain or acquire daily living skills. The dlp monitored patients' nutrition, hygiene, physical health, and budgeting, other needs, and trained skills as required - at home, with family or friends, or at work.

6) Support and education of people important in daily life (see 2) above).

7) Advocacy for patients individually and as a group (see 2) above)

Dlp staff: The dlp team began with 7 psychiatric nurses (a senior nurse, 3 charge and 3 staff nurses), a psychiatrist (senior registrar), and a coordinator. It took 10 months to recruit a social worker, who left after 14 months, after which no other could be found. A senior occupational therapist joined in year 2. From 1988 the 7 nurses were a senior nurse (I grade), 2 senior charge nurses (G) and 4 charge nurses (first F, later G). JC was the responsible consultant and had 2 sessions a week with the team. IMM was responsible for evaluation and training; neither he nor the evaluators were involved in clinical decisions.

Standard control inpatient-followed-by-outpatient care

Control patients had the usual inpatient care given to SMI emergency admissions, in 1 of 10 BM wards in 1 of 200 beds for acute psychiatric care (i.e. 1 bed per 1000 of the catchment area population, over double the national average - Hirsch 1988). A 25-bed ward usually had 1-2 consultant psychiatrists, a senior registrar, 2 registrars, about 16 nurses including 2 student nurses and a senior charge nurse, an occupational therapist, and some psychologist, social worker, and community psychiatric nurse (CPN) input. How problem-oriented the control care was varied. After discharge, controls usually had outpatient appointments. In case of repeated default a CPN would try to reestablish contact.

Catchment area non-health care facilities:

These were sparse. Most of those available could be used by both d1p and control patients, including: drop-in/day centre/luncheon clubs; counselling support; music workshops; recreation, community resettlement and vocational rehabilitation centres; ethnic, social and community projects, swimming pools, training workshops and day care facilities.

EVALUATIONRating times

Rating was an arduous task. Baseline ratings were mostly completed within 72 hours of entry. Subsequent ratings were planned at 3, 9 and 18 months after entry where possible, but many were delayed and so will be called the 4-, 11- and 20-month ratings. Their times varied because many cases, especially controls, were hard to trace and did not answer phone messages or letters. When traced many failed appointments, often repeatedly. After 3 'no-shows' the rater(s) visited their home to make an appointment, which too was often not kept. As a last resort £20 was offered. This was accepted by 20 patients in each group at 4 and at 11 months, and by 78 (37 d1p, 41 control) at 20 months.

Raters

There were 10 PSE-trained raters, mostly psychologists or psychiatrists. New raters observed veterans until they could work alone. All were independent of d1p and inpatient staff and did not discuss clinical status with them. For safety raters had to ask carers about risks during the coming interview, and so could not be blind to treatment group. Where risk was high 2 raters attended the interview, which took place in the research office far from the d1p headquarters, or in the patient's home or the ward. Interviews took over 2 hours to complete on average, often over several visits. Including time to arrange appointments and travel, each rating set took a mean of 5 hours or

more to collect, due mainly to patients' elusiveness.

Measures

Ratings other than satisfaction were made by the raters (see Appendix).

RESULTS

Interrater reliability

Interrater reliability interviews were performed involving all raters. The measure of agreement across all raters was intraclass correlation (r) - r was: GAS .70, BPRS .83, PSE - Total .84, DAH .89, BSO .87, SNR .79, NSN .84. Agreement was thus satisfactory. r for PSE Index of Definition was .69.

Data collected:

Dates and durations of inpatient admissions were available for all 92 dlp and 97 control patients. Baseline ratings were almost complete on most measures. Patient resistance made later ratings vary in timing and completeness, though 94% of all patients (92% dlp, 95% controls) had at least one post-baseline rating (TABLE 1).

Both the baseline demographic features and the clinical ratings of patients who were or were not rated later had been similar except that missing ratings were fewer among dlp men than control men ($p < .04$) and among dlp 'old' vs control 'old' patients ($p < .05$). The reasons for missing ratings at 4m were more often refusal and less often being untraceable for dlp vs controls; these differences were less at 11m and in the reverse direction at 20m, when 19 cases refused (6 dlp, 13 control), 1 was untraceable (control), 6 were dead (4 dlp, 2 control), and 9 were abroad (5 dlp, 4 control).

Patients' baseline features

Of all cases 65% were would-be new admissions. The great majority of baseline features examined (TABLE 2) were balanced across the dlp and control groups: mean age was 34, 49% were male, 40% lived with no support (alone or single with young children), and only 35% had a paid job. The dlp was less

severe on SAS extended family (.04). Ethnic background was like that in South Southwark: 63% British/Irish, 23% Afro-Caribbean (only 5% more than the area norm), 14% other.

PSE diagnosis was: 49% schizophrenia, 17% mania, 19% depression, 3% unclassifiable, 12% neurosis (regarded as SMI by the EC psychiatrist just before randomisation. Schizophrenia was diagnosed more often in Afro-Caribbean than British-Irish patients (70% vs 40% $p < .009$).

At baseline, dlp and control patients had severe psychopathology (TABLE 2). On unpaired t tests, the dlp vs control groups did not differ. Dlp manic patients were more severe than control manics. Dlp 'old' patients had less severe PSE neurotic subscores vs control 'old' cases ($p < .009$ SNR, $< .003$ for NSN) and also vs new dlp patients ($p < .009$ for SNR and for NSN), due to less neurotic subscores among the schizophrenic, not neurotic, patients.

Both the dlp and the control groups had 8 (9%) patients with past psychiatric admissions outside the BM. Across diagnostic subgroups fewer dlp than control patients were 'old' BM cases (17 vs 34, 18% vs 35%, $p < .01$). Fewer dlp than control patients (21% vs 33%, p ns) entered the study on a Mental Health Act Section decided by the admitting doctor. Some dlp patients due for admission on Section were taken home instead.

Outcome

Length of inpatient stay (in days): This was nearly 80% shorter for dlp vs controls, independent of new vs 'old' patients and of diagnostic subgroup. The number of days spent as inpatients was only about 22% as long for dlp vs control admissions (TABLE 3A). Only 3% of dlp vs 34% of controls remained as inpatients throughout the entire first 3 months of the study, and 0% vs 1% for its whole 18 months (TABLE 3A)

Mean number of days out of hospital between initial and any re-admission was:

For dlp vs control: 0- 9 months: 62 (median 31) vs 60 (median 34)

0-18 " : 96*(median 41) vs 119 (median 68)

(*see below)

6 patients (2 dlp, 4 control) were transferred to long-stay inpatient care during the 18-month study period.

Number of admissions: The proportion of dlp patients for whom dlp care prevented any admission at all was 29% at entry, 21% at 3 months, 17% at 9 months, and 12% at 18 months. This estimate is conservative, as 11 (12%) to-become-dlp patients were admitted overnight and randomised the next morning, some of whom were called dlp admissions even if they were immediately thereafter given dlp care at home. All controls were admitted. Total number of admissions was 160 for dlp and 159 for controls. The proportions of dlp and control patients having various numbers of admissions appear in TABLE 3B. The brevity of dlp admissions led to very little rise in their number. Readmission had been required:

by 9 months, for 27% of dlp vs 23% of control patients

" 18 " , " 38%* " " " 35% " " "

Removing dlp responsibility for discharge from any inpatient phase of care prolonged admission: A natural experiment occurred from a change imposed by a BM Audit 31 months into the study (*see below). For the next 13 months (including early in a subsequent controlled dlp withdrawal phase) the Audit transferred the responsibility for discharging dlp inpatients' care from the dlp to the ward team, aiming to increase ward medical input and documentation. 17 dlp patients had admissions during both the pre-Audit 31-month period (47 admissions) and the post-Audit 13-month period (27 admissions). For these 17 cases, from the pre- to post-Audit phases mean admission lengths rose strikingly by 300% from 20 to 60 days ($p < .001$, Wilcoxon $z = -3.24$).

In brief, only 12% of dlp patients had no admission over the 18 months. Dlp and control patients had a similar mean number of admissions and of

readmissions; these were nearly 80% shorter among dlp than control patients when the dlp team was responsible for discharge from any inpatient phase of care. Removing this responsibility trebled admission length.

Clinical function

Dlp and control patients were compared at baseline and subsequently (at 4, 11 and 20 months). For each time on each measure calculation was made of means, standard errors (se's), 95% confidence intervals, and an analysis of covariance (ANCOVA) with the month 0 score as covariate (the satisfaction scales had no month 0 rating and so were studied with t tests).

For each measure the mean change (and its se) from baseline to 4, 11 and 20 months appears in TABLE 4.

POST-BASELINE:

Both dlp and control patients improved significantly by 4 months on all clinical measures (GAS, PSE, BPRS, SAS). This improvement remained stable to 11 and 20 months, even though overall each group contained relapsing patients. The few between-group significant differences favoured dlp over control patients and were mainly at 20 months. Outcome did not favour control hospital over dlp care on any measure, whether for groups as a whole or for subgroups.

Groups as a whole: (Significance of dlp vs control appears in brackets)

GAS (score range 1-100): Mean score in both groups improved from about 32 (marked impairment) at baseline to about 60 (mild to moderate problems) at 4m and 11m, and 64-70 at 20m. For the superiority of improvement in dlp over controls, $p = .08$ at 4m; $.09$ at 20m.

PSE: Total: The marginal dlp superiority over control was not significant at 4 and 11m and was a trend ($.09$) at 20m. Psychotic decreased more than neurotic symptoms within both groups. On syndrome subscores, dlp was superior to control on DAH at 4m ($.03$) and tended to be so at 11m ($.07$) but not at 20m, and at 20m only was superior on SNR ($.04$).

BPRS (theoretical score range 24-168): In both groups scores improved from about 52 at baseline to 37-40, more for dlp than control patients, but dlp superiority was only significant at 20m (.03).

SAS: Dlp improved more than control patients only at 20m, when dlp was superior to controls on global (.03), parents (.002), and extended family (.08), and on a non-SAS scale concerning daily living skills (.03). At 20 months, only 19 (25%) dlp and 18 (24%) control patients had a paid job.

Satisfaction:

Patients and relatives were satisfied with both forms of care. However, their satisfaction was even greater with dlp than control care (FIG 2), both in new and in old patients, and with schizophrenia and with other diagnoses.

Patient's scale: The greater satisfaction with care of dlp than control patients was marginal at 4 months (when many controls were still inpatients) but became highly significant by 11 months ($p < .009$) and remained so at 20 months ($p < .009$). Dlp superiority was highly significant on each of the 8 scale items.

Relative's scale: The patient's relative was more satisfied with dlp than control care by 4m ($p < .11$), and remained so at 11m ($p < .001$) and 20m ($p < .05$). At 11m, greater satisfaction with dlp than control care was significant on 11 of the 13 scale items. If relative's satisfaction is an indirect guide to family burden, then the burden was less from dlp than control patients.

There is a caveat about results with this scale. At 20m, only 53% (76) of all rated patients were living with a relative. Among these, a relative's satisfaction rating was obtained in only 61% (24/39) of dlp and 46% (17/37) of control patients. Cases living with relatives who did, compared to those who did not, rate relative's satisfaction had similar distributions of sex, age, diagnosis and ethnicity, and gains on the GAS. Slightly more patients with a relative's rating were new rather than readmissions.

Subgroups: (ANCOVAS on all measures except t tests for satisfaction)

On the few measures where dlp and controls differed significantly, this always favoured dlp from 11m onwards in the different diagnostic subgroups (schizophrenia, mania, depression) and in the readmitted ('old') and new admission subgroups (TABLE 5).

In brief, control care was never better than dlp care. Dlp improved significantly more than controls: at 4m, on symptoms only on PSE-DAH and BSO, and on patient satisfaction; at 11m, only on patient and relative satisfaction; at 20m, on symptoms (BPRS, PSE-SNR) and social adjustment (SAS global, parents, daily living skills), and patient and relative satisfaction.

Naturalistic observations:

Patients and relatives often showed appreciation when admission was prevented even for severe crises, once they learned that the dlp would give constant support at home. Relatives rarely objected to a patient's discharge after brief admission, and continued contact with the dlp even when patients did not. Patients' satisfaction was reflected in their very low dropout rate. Only 3 refused contact with the dlp beyond the first few weeks; they had entered with acute neurotic problems which required no further care by then. Some patients refused to see the dlp team but returned later for help with problems like finances, housing and work. Others returned to the dlp base and not the Emergency Clinic when they relapsed. Poor initial adherence to medication in about 20 patients (mainly younger men with repeated past admissions) improved somewhat over 12-18 months. The dlp had very few dropouts, even from young Afro-Caribbean schizophrenic men living alone whom some find hard to engage.

Deaths and adverse media coverage:

The cohort of 189 patients had 5 deaths from self-harm in the 20-month study (3 dlp, 2 control). As with SMI suicides in Madison (Cohen et al 1990)

such deaths were unexpected and occurred despite recent contact with staff.

The 3 dlp deaths from self-harm occurred 4, 6 and 17 months after randomisation, and were all in depressives: none were schizophrenic: -The first, a manic-depressive, was offered admission and antidepressant medication 8 days before his death but refused both and was deemed not sectionable; when seen the day before he died he was judged as improved. -The second patient was depressed and alcoholic. After 6 months abstinence he restarted drinking and suicided 2 days later. -The third patient was a manic-depressive with 4 admissions over the last 11 years. Admitted on Section by the dlp team, he went home after 4 weeks on pimozide and dlp care. A year later he moved to Banbury but refused a dlp offer of local psychiatric referral; the local GP was told and the dlp continued to see and phone the patient. He had 95 dlp contacts over 17 months, the last time, with his mother, being 13 days before his suicide, when he seemed well and asked for and accepted more pimozide.

The dlp team saw the 3 future suicides frequently including in the period shortly before their death. It seems unlikely that the control patients would have had such intensive outpatient care. It is also hard to contend that the dlp had a bias against admission given that 88% of dlp patients were admitted at some time, often repeatedly. All 3 suicides were by car exhaust fumes. These deaths could not have been imitative (which might have been the case during inpatient care) as the patients had no contact with one another.

The 2 control deaths from self-harm were 7 and 11 months after study entry. -The first had had 7 past admissions for psychotic depression and had made repeated serious suicide attempts. 5 months after discharge she refused readmission when paranoid ideas recurred. She was seen 2-weekly, but died of an overdose. -The second was admitted for the first time, for gross self-neglect, and was discharged after 3 months. She failed 2 OP appointments and had no more follow up. 9 months later after neighbours complained of the smell

she was found dead in her bath with signs of neglect as before.

Several dlp and control patients made serious suicide *attempts* and some threatened others. Information is too incomplete to compare the 2 groups. More is known for inpatients, and for dlp patients while outside hospital (most of the 20 months post-entry) as dlp staff regularly contacted patients and their families despite abscondment whereas controls lacked such assertive outreach. Indeed this was one reason why the dlp project was begun in the first place. At least 1 dlp and 4 control patients made serious suicidal attempts as inpatients (1 control while under 24-hour observation).

The cohort had 1 other death within the 18-month study period - a dlp patient, from cancer of the cervix 12m post-entry.

Ten months into the study and 7½ weeks after trial entry a dlp patient aged 45 killed a neighbour's baby. During 5 days as an informal inpatient he was wary but coherent and rational. Repeated examination found no psychotic signs. With the ward team's agreement he was discharged into intensive CC and though elusive was seen repeatedly at home and at the dlp team's base. He managed well and found a job. Two days after he was last seen he suddenly killed the child and revealed previously concealed paranoid ideas. He was transferred to a special secure hospital. A local newspaper report of the murder roused little attention. 14 months later 4 national newspapers and TV news suddenly headlined the murder and the suicides (Marks 1992).

The homicidal and the 3 dlp suicidal patients had had unusually persistent care from the dlp. Had the homicidal man remained an inpatient he could have discharged himself, avoided outpatient followup, and become someone for whom district services could disclaim responsibility. The dlp's assertive outreach, in contrast, ensured its continuing responsibility for this case and for the future suicides, who with control care may well have dropped out by the time of their tragedies and been then regarded as outside the clinicians'

responsibility. A Maudsley Audit exonerated and praised the dlp team, and the Ethical Committee allowed the study to continue. Outside the dlp study, among inpatients and newly discharged cases in the 480-bed Bethlem-Maudsley Hospital suicides were found to occur, surprisingly, about once in 7 weeks.

DISCUSSION

Outcome was rather better with home- than in/outpatient care

SMI patients facing emergency admission did better with CC (dlp) support than with control care lacking such support. Dlp superiority was marked in greatly reducing bed-day numbers from the start, was slight on symptoms, was greater on social adjustment at 20m, and was impressive on patient and relative satisfaction at 11m and 20m. Some dlp superiority appeared in each diagnostic subgroup and in readmitted as well as new patients.

Inpatient use with CC

The dlp bed-day reduction was 80% when the dlp team controlled discharge from any crisis inpatient phase. However, when after a media scare a BM Audit transferred this responsibility to the ward team in the last few months, dlp crisis admissions for the same dlp patients lengthened three-fold. This occurred despite the availability of dlp CC continuing after discharge. The patients were not tertiary referrals. Clinicians' attitudes may partly decide duration of stay.

The pre-Audit bed-day reduction was due mainly not to dlp care being home-based, but rather to the dlp team's control of discharge from any admissions. A drop in bed days was the most important factor in making the dlp less costly overall than control care (Knapp et al 1993), even after correcting for the greater mean length of BM admissions compared to those in other hospitals. For maximum benefit the membrane between hospital and community care must be permeable.

In other controlled studies too (Herz et al 1975; Knights et al 1980;

Kennedy & Hird 1980) outcomes were as good with brief as longer admissions. Comparisons of mean durations across studies and hospitals, however, are difficult as one first has to standardise: whether admission was in an emergency, problem severity and duration, clinical outcome, community resources, and teaching and research functions of hospital.

Among 136 South Southwark patients outside the dlp study who were admitted to the BM over 3m in 1991 (Bebbington & Feeney 1991) the median length of BM admissions was 20 days, far less than the 53-day median admission length of dlp controls just after study entry in 1987-9. Compared to dlp study patients the 136 patients were also far less often admitted from the EC (46% vs 98%), had more support at home (fair/good in 84% vs 60%), were older (41 vs 34), and were slightly less often admitted as an emergency (86% vs 100%), but had similar numbers who were female (53% vs 51%), on Section (24% vs 27%), and of Afro-Caribbean origin (24% vs 23%).

The far longer admissions of dlp controls than of BM catchment area patients outside the study might be due to more of them being disturbed and having less support at home - the dlp's home support may have helped cut dlp inpatient stays. BM catchment area admissions might have also shortened in 1991 from clinical practice being influenced by the dlp results and by other factors. Bebbington & Feeney concluded that BM admissions had been for good reasons and recommended that the BM extend dlp-type outreach. The BM sectorised its district service and gave CC teams the control over bed use which the dlp had found is essential if inpatient bed use is to be reduced.

Dlp care did not reduce the **number** of admissions, though it saved the use of about 10 beds as long as the team ran both CC and ward care. Even with CC, however, some inpatient beds are still needed to deal with crises. Fully 88% of dlp patients had to be admitted at some point, 71% at entry and 17% later. We do not know how many admissions might have been averted had more

help at home or a non-hospital crisis bed been available. The number is probably small given the intensive dlp help patients received in crisis, including several home visits daily if necessary. It may be easier and cost less to admit patients briefly for tiding over a major crisis provided that inpatient stay does not drag on subsequently.

Apart from its need for access to crisis beds, CC does not abolish the need for a very few chronic admissions. One dlp patient became a detained long-stay inpatient and remained so 30 months post-entry. The homicidal patient went to Broadmoor.

Though BM ward staff levels seemed above national ones, actual clinical time was markedly reduced by the BM's research, development and training functions. A consultant coming from an impoverished district hospital to work in the BM noted that the BM had even fewer whole-time equivalent sessions available for clinical work (Strathdee perscom) because of duties special to a postgraduate teaching hospital. Because BM admissions last longer than the UK average for similar patients and outcomes, dlp care elsewhere might shorten inpatient stays less. However, the superior outcome of dlp on social adjustment and on consumer satisfaction is a benefit worth having anywhere.

Patient satisfaction and family satisfaction and adjustment

On the SAS parent subscale, for the minority of patients rated on this (mostly living with parents), dlp was superior to control care at 20m. Only about half of all patients lived with a relative at 20m, of whom only half had a relative rate satisfaction. Outcome on this scale accords with 1) the relative's greater satisfaction with dlp than control care, and 2) the dlp superiority at 20m on daily living skills (a subscale rated by most patients).

More consumer satisfaction with the dlp was evident by 11m and continued at 20m. The dlp's superiority on relative's satisfaction and relationships with parents does not confirm views that good community care inevitably adds

burden to the family.

Relatives were satisfied with dlp care despite the far shorter time which dlp cases spent as inpatients. Dlp patients may have become easier to live with after training in daily living skills and improving more in these and in social adjustment. However, dlp superiority on these variables only appeared at 20m but was most significant for relative's satisfaction at 11m.

Perhaps too, the longer time that controls spent as inpatients, with their families having little contact with them or their clinicians, had alienated control patients from their relatives and begun a process of institutionalisation. Dlp patients had more chance to maintain social ties, being away from home for far less time, and with the dlp team giving frequent support to their families.

Our disturbed patients did not do better in wards monitored 24 hours a day. The slightly better outcome from, and preference of patients and their relatives for, well-supported care outside hospital meshes with other advances in acute and chronic health care. Women often prefer to give birth at home, and it is now common to have hospital day surgery and other major procedures with aftercare at home.

The catchment area was deprived

The dlp results were obtained in the inner-city catchment area of South Southwark (part of the former borough of Camberwell) in SE London. Its population was 136000, of whom 88000 were aged 16-64 in the 1981 Census, and 22% lived in households whose head was born in the New Commonwealth or Pakistan. In 1981 Southwark was the eighth most deprived borough in the UK on Jarman social indicators. In 1989 Camberwell health status was worse than average on Standardised Mortality Ratios for people aged <65 for suicide, injury and poisoning, and traffic accidents.

The present outcome in a deprived UK area accords with that obtained in

previous controlled studies in better off areas of Madison and Sydney, which lasted for 12 months. The proportion of bed days saved was about 80% in all 3 studies. Although our scales differed from those used in Madison, the changes were similar. Some of our scales were like those in the Sydney study - the amounts of improvement on the GAS, BPRS, PSE, social adjustment and in patient and relative satisfaction were comparable.

Caveats

The present study recruited patients mainly from a walk-in Emergency Clinic which very few hospitals have. It is hard to know whether such patients differ in important ways from those admitted in crisis from other sources.

Our study's design does not allow us to say how much the superiority of home-based dlp care was due to its i) *being based at home* (i.e. to community care per se), ii) *being problem-centred*, iii) *teaching of daily living skills*, iv) *assertive followup*, v) *one team carrying out all care components rather than delegating them to several agencies*, vi) *other ingredients*. Differently designed studies are needed to answer such questions.

Only 1 patient refused study entry, and very few dlp cases dropped out of treatment. However, both groups had attrition in the numbers rated post-entry. Some of this may reflect the long time that ratings took as well as SMI patients' usual reluctance to participate. High attrition in SMI studies is common. At baseline, patients who were later rated at 20m had been similar to those who were not so rated.

It is unclear why fewer dlp than control patients had been previously admitted to the BM (but not to psychiatric hospitals overall). We could find no evidence of bias affecting the randomisation. The dlp and the control groups had similar severity at baseline, and the dlp superiority over the controls was present even in the readmitted 'old' patients.

A mechanism is needed to pay staff small amounts to be on an after-hours

bleep rota for the few occasions when telephone advice is needed. Patients and relatives are reassured by this help-line even though they rarely use it. Its small cost prevents some disruptive and expensive crisis admissions. A further cost-effective payment is for quick forms of staff travel to patients' homes and other sites in order to deliver good community care.

Deaths

Over the 20 months post-entry there were 3 dlp and 2 control deaths from self-harm, and a homicide by a dlp patient. Enquiry into the dlp deaths found nothing the dlp team could have done to prevent them; there was no enquiry into the control deaths. SMI patients often kill themselves whether cared for as inpatients or after discharge. CC patients suicided during followup in Madison too despite good support (Cohen et al 1990). Intensive CC for SMI does not reduce deaths despite the other gains it may yield.

Suicide is far more common in a SMI than a general population e.g. for inpatients (Anderson et al 1991) and after discharge from Northwick Park Hospital (Anderson et al 1991), St Thomas' Hospital (Melzer et al 1991, and in Torbay (Morgan 1992) and SE London (Wilkinson 1982). Such common tragedies draw less attention if they occur in routine care than in a new project.

Training and skill mix

The dlp team consisted mainly of psychiatric nurses. The optimal professional mix is hard to decide. Efficiency may depend more on skills in problem-centred and other community care of SMI than on professional background. Good problem-oriented CC needs training (Kennedy & Hird 1980) and at the start such had not been developed for SMI.

Training including dlp-type problem-centred CC for SMI is now part of the Thorn nursing course in London and Manchester. Such training should hasten the spread of problem-centred CC in the UK and reduce the chance of patients being deprived of helpful medication and case management.

Round-the-clock care

The dlp's hours of cover, and its team size, were fixed by resources available. Hours were initially 08.30-21.00 weekdays, 09.00-17.00 at weekends, and team telephone cover outside those hours. Visits to patients at night were not carried out as they would have required 2 professionals for safety reasons and so were too costly. Telephone contact often defused the problem and reassured. If this failed, which was very rare, the patient was asked to come by minicab to the EC. A few brief and perhaps avoidable admissions ensued largely because the EC staff did not know the patients. The cost of such admissions has to be weighed against the cost of 24-hour CC.

Resistance to change

Care innovations commonly generate resistance in most settings. Much negotiation was necessary within the BM before our study could begin and many were skeptical about its value. Some dlp staff were reluctant to use the problem-centred approach. The leak to the media that began the adverse coverage may have been internal. Difficulties then arose from the media ordeal and uncertainty about the dlp's future. Later CC developments by the BM were eased by the ground having been broken by the dlp (Strathdee, perscom).

The limits to gains from community care (CC) for SMI

Though CC was superior to standard in/outpatient care in some ways, it did not work miracles. Symptoms and social adjustment were only slightly more improved, and some patients refused medication. In both groups the number who were unemployed actually rose by the end of the study (Knapp et al 1994). Some cases still required considerable care time even 20m after study entry.

When the dlp matched staff time invested to clinical progress achieved (Connolly et al In Preparation) it highlighted a major point for care delivery. To maintain asylum functions in good CC, key workers must coordinate many different resources and regularly visit defaulters. This drains staff

time. With unresponsive patients the load never stops, year in and year out, taking hundreds of hours of staff time a year, more during crises and less between, but never zero. Though a problem-oriented approach seems to reduce the time needed, the burden on carers remains great in tough cases.

The heavy load from SMI patients contrasts starkly with the far lighter demand on staff time made, say, by behavioural treatment of anxiety disorders (Marks 1992). This is not because all anxiety disorders are less severely disabling than is SMI. They can be just as crippling. The contrast in staff time needed stems, rather, from the greater efficacy of certain treatments for some conditions. Ten hours of clinician time spent in appropriate behavioural treatment of severe chronic anxiety disorder can yield major and lasting improvement. Not so with chronic SMI. Even the best medication plus psychosocial treatments still yield only modest gains in chronic schizophrenia or manic-depressive illness, and these need much organisation and staff time.

Perverse incentives against assertive outreach

The dlp's media ordeal uncovered an ironic and uncomfortable paradox in good CC. Had the dlp man who became homicidal been in control care he could have discharged himself, avoided followup, and the service could have then disclaimed responsibility. The dlp's assertive outreach, in contrast, ensured its continuing responsibility for this case and for the future suicides, who with control care may well have dropped out by the time of their tragedies and been then regarded as outside the clinicians' responsibility.

A good CC team's assertive outreach for absconding SMI patients increases its vulnerability to criticism should anything go wrong. Keeping in touch greatly prolongs the period during which the team is held responsible for the case and thus for any adverse events, which are common with SMI. Adverse events in someone having no CC, however, are less likely to be linked to and blamed on the clinician. This perverse incentive to drop difficult

patients opposes good CC, and is seen in road accidents too. A doctor driving by who stops to care for the injured becomes vulnerable to a malpractice suit, whereas the unknown doctor who drives on without giving help incurs no liability. The law does not favour Good Samaritans.

Vulnerability of good home-based care

Sound community care is a fragile plant. It withers quickly if policies do not ensure: secure funding which omits perverse incentives that impair good care; careful organisation; access to quick specialist help and brief crisis admission; enough staff trained in problem-oriented case management; an after-hours telephone rota; quick staff travel to patients' homes from the work base; systematic audit; coordination of the CC team with the many agencies relevant to SMI care.

Unless all the above conditions are satisfied the modest benefits from CC seen in research studies like the present one are easily lost. Over the 15-month controlled withdrawal phase which succeeded the present study the benefits largely disappeared apart from consumer satisfaction (Marks 1994).

CONCLUSIONS

1. Over 20 months home-based care improved symptoms and social adjustment slightly more than standard in/outpatient care, and was definitely preferred by patients and relatives. Home-based care reduced the duration (but not number) of crisis admissions by at least 80% as long as the community team was responsible for discharge. Cost was less. Beyond the 20-month study consumer satisfaction with CC continued despite loss of most other gains.
2. Good CC in no way cured SMI. It did not reduce suicides. Many patients continued to have marked symptoms, be unable to work or live with their families, and to require assertive outreach indefinitely.
3. For home-based care to benefit patients more than in/outpatient care it must have: i) staff who are well-trained and persistent yet have realistic

expectations, ii) a community team responsible for any brief inpatient phase of patient care; iii) a Health Authority which strongly supports community staff with funding and policies to assist home-based care.

4. Differently designed studies are now needed to test which components of home-based care were responsible for its superiority over standard care, and how to sustain it indefinitely.

THANKS AND ACKNOWLEDGEMENTS: The Department of Health funded the great bulk of this study's clinical and evaluative work, including some of the raters from Professor Rachel Rosser's team at the Middlesex Hospital. The King's Fund funded a part-time rater, and the Wolfson Foundation funded part of the analysis. Dr Martin Marlowe helped to analyse the numbers of dlp contacts. We are indebted to Drs John Houtt, William Knoedler, Len Stein, MaryAnn Test and Debbie Allness, for advice in setting up and running the study. NATO and the Bethlem-Maudsley Hospital funded transatlantic cooperation. Valuable comments on the manuscript were made by Professors Francis Creed and Peter Tyrer, Dr Geraldine Strathdee, and the Department of Health.

APPENDIX: EVALUATION INSTRUMENTS

Global assessment scale (GAS): (Endicott et al 1976; Luborsky 1962, and adopted as axis V in DSM-III-R). 1=very severe illness, 100=perfect health.

Present state examination (PSE), 9th edition: (Wing et al 1974, Cooper et al 1972, WHO 1973, Wing & Sturt 1978). The Catego program processes 140 symptom items (each absent, questionable or present) into 1) 38 syndromes and four syndrome subscores [DAH (delusional and hallucinatory syndromes, BSO (behaviour, speech and other syndromes, SNR (specific neurotic syndromes), NSN (non-specific neurotic syndromes)]; 2) total score which can measure change (Leff & Wing 1971); 3) Index of Definition (ID); 4) ICD-9 diagnosis.

Brief Psychiatric Rating Scale (BPRS): (Overall & Gorham 1962, Lukoff et al 1986, (Hedlund & Vieweg 1980). 24 symptoms over the 2 past months each scored 1 (not present) to 7 (severe).

Social Adjustment Scale (SAS): (Weissman et al 1971, 1974) 48 items each scoring 1-5 (1 = normal). Areas covered are role performance, interpersonal relationship and work satisfaction (worker, housewife or student) (6 items); social and leisure activities (11 items); extended family (8 items), marital (9 items); parental (4 items); family-unit (3 items); economic adequacy (1 item); overall adjustment (1 item). This study used i) the mean score of all individual items divided by the number of questions, ii) subscore totals for the various areas, and iii) global adjustment. To the SAS we added a subscale daily living skills, also scored 1-5, on how well in the previous month the patient had done housework, laundry, shopping, preparation of meals, and friction/distress/satisfaction concerning these.

Satisfaction with the service:

1. Patient's scale: (Larsen et al 1979, Attkison & Zwick 1985, Lemmens & Donker 1990). 8 items, each rated 1-4 (4 = very satisfied). Total score range 0-32. The 8 items are: (*Quality of service you have received? Kind of*

service you wanted? Met your needs? Recommend program to a friend? Amount of support received? Helped you deal more effectively with your problems? Overall satisfaction with service? Would you come back?)

2. Relative's scale: 6 items on the needs and satisfaction, and 5 on the quality of service, for relatives, plus 2 questions on both aspects. All items rated 1-5 (5 = very satisfied). Total score range 0-65. The scale was developed for this study out of the Patient's scale.

Economic Questionnaire: See Knapp et al 1994.

Time of post-baseline ratings

(m=months, se=standard error; dlp vs control p ns)

actual timing

Age	Group	Mean	SE	Controls	SE
3-6 months post-entry	dlp	3.9m	0.2	4.1m	0.2
9-14	"	11.1m	0.2	11.3m	0.2
15-30	"	20.5m	0.3	21.0m	0.3

Percentages of all 189 patients who were rated

At baseline, 99% (99% dlp, 98% control) n's = 91 dlp, 95 control

" 4m, 70% (74% " , 63% ") " 68 " 61 "

" 11m, 70% (72% " , 67% ") " 66 " 65 "

" 20m, 75% (78% " , 73% "). " 72 " 71 "

TABLE 2: DEMOGRAPHIC AND DIAGNOSTIC FEATURES OF SAMPLE

	DLP		CONTOL	
	n= 92 (100%)		n = 97 (100%)	
Mean age	33.4	s.e. 1.2	35.0	s.e. 1.1
Male	48	52%	46	47%
Female	44	48%	51	53%
British/Irish	57	62%	63	65%
Afro-Caribbean	23	25%	20	21%
Other ethnic	12	13%	14	14%
First Admission	67	73%	55	57%
Previous Admission	25	27%	42	43%
No home support	33	36%	44	45%
On section MHA at study entry	19	21%	32	33%
Schizophrenia	45	49%	48	49%
Mania	14	15%	18	19%
Depression	21	23%	24	25%
Neurosis	9	10%	14	14%
Unclassifiable	3	3%	2	2%

TABLE 3: Number of days spent as inpatients, and number of admissions
A. NUMBER OF DAYS SPENT AS INPATIENTS:

i) For all admissions:

No. of inpt days:	DLP			CONTROL			P
	mean (median) se			mean (median) se			dlp v con
during first 3mths	13	(5.0)	2.4	82	(41.0)	9.7	<.009
" " 9mths	14	(7.0)	2.3	81	(36.5)	3.4	<.009
over whole 18mths	18*	(8.5)	2.3	76	(38.0)	7.8	<.009

ii) For shortest and longest admissions only:

DLP % CONTROL %

Fewer than 15 days	during first 3mths	72	18
	" " 9mths	66	15
	" whole 18mths	44*	17
More than 100 days	during first 9mths	3	38
	" whole 18mths	11*	42

iii) Initial vs Re-admissions:

	DLP				CONTROL				P
	Initial mean se		Readmis mean se		Initial mean se		Readmis mean se		dlp v con
9mths	18	5	10	2	45	10	70	15	#<.02
18mths	16	12	26*#	4	82	17	72	16	

B. NUMBER OF ADMISSIONS:

	No of adms	DLP %	CONTROL %
by 9mths	1	55	77
	2	15	29
	3	9	2
	4	2	2
	5 or more	1	0
by 18mths	1	50	65
	2	17	20
	3	5	10
	4	9*	2
	5 or more	7*	3

* = see text re post-BM-Audit loss of dlp control over any inpatient phase

Table 4A: OUTCOME OF CLINICAL AND SATISFACTION MEASURES
 mean, se (standard error), n (no. of patients per cell)

		DLP			CONTROL			CONFID INTERV			ANCOVA
	Month	mean	se	n	mean	se	n	95% C. I.			P
GAS	0	33.0	1.5	91	33.8	1.5	95				
	4	60.1	2.1	68	55.0	2.2	61	(-5.1)	-1	to .6	.08
	11	63.0	2.2	66	59.5	2.6	65				ns
	20	70.1	2.1	71	64.4	2.2	71	(-5.4)	-12	to .7	.09
PRS	0	52.2	1.6	91	51.3	1.8	95				
	4	39.3	1.6	68	41.4	1.5	61				ns
	11	37.7	1.4	66	39.7	1.5	65				ns
	20	35.1	1.3	71	39.6	1.7	71	(4.4)	.4	to 8.5	.03
SE Total	0	28.2	1.5	89	28.4	1.4	95				
	4	13.5	1.4	67	16.5	1.5	61				ns
	11	11.8	1.5	64	13.8	1.8	64				ns
	20	8.2	1.1	72	12.2	1.8	70	(3.7)	-.5	to 7.8	.09
PSE DAH	0	5.6	.7	89	5.1	.8	95				
	4	4.4	.8	67	2.9	.8	61	(1.4)	.15	to 2.6	.03
	11	3.5	.8	64	2.6	.7	64	(1.3)	-.09	to 2.8	.07
	20	.9	.3	72	1.5	.3	70				ns
PSE BSO	0	4.9	.5	89	5.4	.5	95				
	4	3.9	.7	67	3.3	.6	61	(.9)	-.02	to 1.9	.05
	11	2.8	.6	64	3.8	.6	64				ns
	20	1.1	.3	72	1.8	.5	70				ns
PSE SNR	0	5.7	.6	89	6.0	.6	95				
	4	2.3	.5	67	2.1	.6	61				ns
	11	2.7	.7	64	2.2	.7	64				ns
	20	1.6	.3	72	2.9	.6	70	(1.2)	.09	to 2.5	.04
PSE NSN	0	11.9	.9	89	12.0	1.0	95				
	4	4.7	.9	67	4.2	1.1	61				ns
	11	5.8	1.2	64	4.6	1.2	64				ns
	20	4.6	.7	72	6.0	.9	70				ns
Patient's satisfaction	4	28.8	.7	61	23.7	.7	54				
	11	27.1	.5	62	22.3	.7	59	(-4.4)	-6.2	to -2.8	.001 !
	20	27.4	.3	69	22.0	.7	68	(-3.4)	-5.2	to -1.6	.001 !
Relative's satisfaction	4	53.5	1.9	23	48.5	2.5	15				
	11	54.4	1.3	23	44.9	2.3	15				.002 !
	20	52.6	2.1	24	45.3	2.6	12				.03 !

= global assessment scale BPRS = brief psychiatric rating scale
 = present state examination; PSE syndromes were:
 H = delusional and hallucinatory; BSO = behaviour, speech and other;
 R = specific neurotic; NSN = non-specific neurotic
 on unpaired t test

Table 4B OUTCOME OF SOCIAL ADJUSTMENT (SAS)
 mean, se (standard error), n (no. of patients per cell)

		DLP			CONTROL			CONFID INTER	ANCOVA
	Month	mean	se	n	mean	se	n	95% C.I.	P
Global	0	4.6	.1	87	4.7	.1	92	(.54) .05 to 1.0	ns ns ns .03
	4	3.4	.2	67	3.6	.2	63		
	11	2.9	.2	59	3.2	.2	61		
	20	2.5	.2	71	3.1	.2	68		
Social	0	3.0	.1	87	3.1	.1	92		ns ns ns ns
	4	2.7	.1	67	2.8	.1	65		
	11	2.4	.1	62	2.5	.1	63		
	20	2.2	.1	71	2.5	.1	73		
Extended family	0	2.7	.1	80	2.3	.1	85	(.41) -.06 to .9	ns ns ns .08
	4	1.8	.1	61	2.0	.1	61		
	11	1.6	.1	60	1.8	.8	59		
	20	1.5	.1	69	1.7	.1	72		
Parents	0	2.3	.2	22	2.1	.2	28	(1.3) .6 to 2.0	ns ns ns .002
	4	1.9	.2	14	2.1	.1	20		
	11	1.7	.2	12	1.8	.1	18		
	20	1.1	.1	18	1.6	.2	14		
Family living skills	0	2.7	.1	66	2.9	.1	61	(.66) .09 to 1.2	ns ns ns .03
	4	2.2	.2	69	2.0	.2	67		
	11	1.7	.1	62	2.0	.2	63		
	20	1.6	.1	68	2.0	.1	67		
Economic	0	2.3	.2	86	2.6	.2	91		ns ns ns ns
	4	2.2	.2	67	2.5	.2	65		
	11	1.9	.1	60	2.1	.2	61		
	20	1.8	.1	68	2.2	.2	70		
Work	0	2.4	.1	42	2.7	.1	58		ns ns ns ns
	4	1.9	.1	35	2.4	.2	33		
	11	1.8	.2	28	1.9	.2	35		
	20	1.4	.1	28	1.7	.2	31		
Vital	0	2.7	.1	30	2.4	.2	27		ns ns ns ns
	4	2.1	.2	19	2.0	.2	20		
	11	1.9	.2	16	1.9	.2	21		
	20	1.6	.2	25	1.7	.2	26		