The South Camden Schizophrenia Survey

An experience of community-based research*

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The South Camden Schizophrenia Survey was started in 1985 with Regional Funding through the Locally Organised Research Scheme. Its overall aim is to explore the disabilities and needs of those individuals recognised by the services within an inner-city area as suffering from schizophrenia. The survey has also been the first step towards setting up a computerised case monitoring system, named 'Safety Net', which is being developed as a means of keeping track of the needs and progress of these vulnerable individuals. This enterprise will develop a community-wide perspective directed at targetting the deployment of services to those most in need. This article gives a preliminary account of the progress so far and highlights our experience of carrying out research within the community.

Mental health policy is committed to the philosophy of community care with the planned closure of the old, large asylums of the previous century. Of particular relevance are the plans by the North East Thames Regional Health Authority partially to close Friern Hospital by 1993 (with the complete closure of services to Camden). Such plans should ideally be developed in the context of a detailed knowledge of the provision of care as it now exists and be incorporated into a means of evaluating an evolving community service as outlined by Wing.[1]

South Camden is an inner-city area of London which is served by Camden Social Services and lies within Bloomsbury Health District. It has a population of around 54,000. Into it drain three major railway termini which connect with the north of the country (King's Cross, St Pancras and Euston stations). It is the first port of call for large numbers of individuals arriving in London, many of whom are unemployed and homeless. The social indices for Bloomsbury indicate the high degree of social deprivation in comparison with other health districts.[2] Previous studies within Camden have highlighted the heavy demands placed upon the psychiatric services.[3,4]

Based upon a talk given at the December 1986 Conference of the Research Register group of the North East Thames Regional Health Authority at Claybury Hospital. Convened by The Team for the Assessment of Psychiatric Services (TAPS) and chaired by Dr B. Heine (Regional Clinical Adviser) and Dr J. Leff (Honorary Director of TAPS).

Outline of the service

In-patient care and day hospital facilities are provided by St Pancras and Friern Hospitals primarily, with occasional recourse to facilities at St Luke's and Middlesex Hospitals. Out-patient management is primarily at University College Hospital and St Pancras Hospital. The community psychiatric nursing service works closely with both psychiatric, primary care and other services in the area. The community psychiatric nurses are based in health centres and day hospitals throughout Bloomsbury, as well as at the Mental Health Unit. They also run depot medication clinics at the Jules Thorn Day Hospital and more recently at the Tottenham Mews Day Hospital.

Day centres are largely located in North Camden except for the Cromer day centre for elderly people. These centres have a variety of orientations ranging from a highly structured approach to a drop-in facility. Recently, temporary closure of a drop-in centre has resulted in difficulties at other day centres where some clients have left in response to an influx of more disabled individuals.

Part III homes are exclusively outside South Camden as are many group homes and foster-care placements. Homeless person hostels provide a much needed facility in this inner-city area. Those located within South Camden are Arlington House providing refuge for some 600 men, St Mungo's Hostel catering for 106 men, Camden Womens' Resettlement Unit providing 40 places, Cecil House (which also caters for female clientele) and the Simon Community Night Shelter providing temporary accommodation for up to three nights. A recent initiative is the 'Compass Project' which will be a shopfront providing a service to the longer-term mentally ill.

The study

The patients included in our survey were those adult patients from South Camden aged 18 or over who were effectively being treated as suffering from schizophrenia on 1 October 1985. A broad definition of schizophrenia was employed and this will later be refined by the application of the Feighner criteria.[5] All patients receiving depot neuroleptic medication were included even if the diagnosis of schizophrenia was not established.

Patients were identified by visiting the relevant agencies outlined above. Letters were also written to GPs, social and probation services in order to identify those individuals who might not be in direct contact with the psychiatric

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service. This was followed up by a further letter, telephone calls and visits to the various people concerned. In this way 480 individuals were identified.

Questionnaire and interview schedules

A detailed questionnaire consisting of 150 items of information was developed for use in the survey. The questionnaire was divided into six sections which could be completed separately if necessary. The information collected included demographic details, service contact, past history, diagnosis and management. Each patient was interviewed using the Manchester rating scale for the assessment of mental state.[6] A best informant was interviewed employing the MRC Social Behaviour Schedule.[7] During the course of the study about 10% of patients are being co-rated to check inter-rater reliability.

Problems of researching in the community

We would like to highlight some of the challenges faced in trying to carry out this research. The first difficulty we encountered was that the number of patients identified was far in excess of the estimate in the research protocol (2.4 times greater). The identification of patients presents particular difficulties in a community survey. The need to identify individuals from a wide spectrum of sources from within and outside the borough, necessitated care in preventing the error of duplicating counts. This was achieved by the allocation of a specific code number to each patient and by the establishment of a temporary administrative database which detailed names, addresses and contacts and was maintained on an IBM PC using the database management package dbase III.

Diagnosis of individuals with no psychiatric contact at the census point often required a detailed search for previous psychiatric contact and an exploratory diagnostic interview. Difficulties were encountered by the authors in attempting to gather the necessary information required in order to apply Feighner's criteria. Particular problems were encountered with those individuals where details relating to premorbid levels of function were scant or non-existent (e.g. the long-stay population). In order to overcome such difficulties 'Feighner' information was gleaned from as wide a variety of sources as possible.

In general terms a wide variety of services expressed interest and enthusiasm in assisting us with the project. Occasionally, however, we encountered difficulties. At some contact points, for instance, the residents were asked as a group by a key worker whether they were prepared to participate in the survey. This initially led to a global refusal. Where possible patients were approached through one of the health workers involved in their care. Occasionally a key worker felt that an interview would be damaging to a relationship that had taken time to establish. We respected these views and some refusals relate to these issues.

Larger organisations were slow to respond to our requests for co-operation. The social services took 10 months to reply to numerous and detailed letters, whereas individual social workers were enthusiastic from the commencement of the project. Finally, interviewing this particular population proved both interesting and occasionally frustrating. In general terms we were struck by the large numbers of individuals living in the community who were preoccupied with psychotic experiences and by those individuals living in squalor, with little daytime occupation and sometimes heavily dependent on relatives. A substantial minority of patients seen for interview were still in bed at three in the afternoon, some interviews being conducted in semi-darkness.

At Arlington House, where there were 600 men, comparatively few individuals were identified for the survey (4% of the total residency). This figure contrasted sharply with that of other homeless person hostels where approximately one quarter of the residents in each hostel were identified as meeting the research criteria. The staff were extremely helpful but residents there tended to live anonymous existences and were often not forthcoming about their lives and experiences. Some patients proved elusive and we received no response despite repeated letters and visits. One resident at Arlington House was particularly difficult to interview. During episodes of psychosis he would climb up the drainpipe and through a window to his room thus evading any contact with staff or researchers. A proportion of individuals were no longer resident at the most recent address detailed in their notes and landlords would tell us that they had moved on some time ago.

The difficulties described caused progress to be slower than anticipated; 480 individuals have thus far been identified although some general practices remain to be contacted. Of this population, 70 individuals have refused to be interviewed.

Case histories

The following vignettes are provided to indicate some of the problems encountered in the community. They are merely a small sample of the many patients who have been seen, yet highlight some of the issues that will need to be addressed if community care is to be a success. The burden on family and health professionals is self-evident from these case histories. There are many more examples which could be quoted. Though analysis of the data will be important in providing a clearer indication of the problem in a more objective way, it is hoped that these short accounts bring the study to life in a more tangible and real sense.

PATIENT A This 70 year-old woman with schizophrenia has had 14 admissions to Friern Hospital between 1953 and 1969. Since 1969 she has had no contact with psychiatrists until an out-patient appointment recently. She is visited regularly by her community psychiatric nurse who provides support to her and her son, in addition to giving her a monthly depot injection. Since her husband died in 1967 of a brain tumour, her son has devoted himself to looking after her and acts as a full-time carer. Recently, the situation has deteriorated because of the son's increasing dependence upon alcohol. Mrs A is constantly hallucinated and displays

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prosectic catatonia (continually whispering under her breath). She is completely blind in her right eye and vision in her left eye is poor due to glaucoma. When interviewed, she responded to questions but had marked poverty of speech. She was depressed and asked the interviewer if he would "end her". She talked openly about hearing voices from the devil calling her a dirty old woman and saying that she is in hell. She was convinced that Satan had killed her in 1950 and talked about being "made as a baby at the university" at that time. She demonstrated temporal disorientation, believing herself to be in her twenties. She claimed that people from Ireland with the surname Clancy controlled her mind and body. They move her lips: "it is them who are talking to you now." She claimed she could not worry because she was dead, saying: "this is not my body, they have changed it. I had a baby body but they have changed it."

PATIENT B This 62 year-old woman was visited at home where she lives with her two sisters. She was not communicative and most of the history was obtained from her sisters. She had not been reviewed by a psychiatrist for over a year and her sisters were now enquiring if there were any better tablets for the treatment of schizophrenia. Miss B appeared withdrawn and required close supervision. She tended to leave on the gas at times, had locked herself out of the flat, and had on one occasion caused a small fire. She required constant encouragement and supervision to bathe and had been sporadically physically violent. Concern was also expressed about her habit of spitting in the street and in the Post Office. Her sisters were unable to comprehend why she habitually concealed religious pictures beneath her bed and Miss B would not discuss this. Service support included a home-help one day a week and meals-on-wheels. Miss B had refused to attend any out-patient clinics and the community psychiatric nursing service had discontinued contact one year ago.

PATIENT C This 57 year-old man was visited at a homeless-persons hostel where he had been living for two years. He was a well-spoken Indian man who had arrived in the United Kingdom in 1958. Mr C admitted to having had one admission to hospital 20 years ago, but was reluctant to speak about this. He had had no medication for many years. According to staff he spent most of his day wandering the streets aimlessly, was difficult to motivate, and had few other interests. His hygiene was poor and he needed frequent reminders to wash. He continually spoke about the impending arrival of three million Martians and about having been swindled out of billions of pounds. It was difficult to get any coherent history as he was totally preoccupied with delusional ideas. He spoke about being continually operated on by "malpractices" and stated that his parents had been killed by these and that injection implants were being used in strategic positions within him. He claimed to be the victim of "blood calculations" from childhood and spoke of "98 repti-universes" which he heard talking to him. He believed there were "80 valid creators" to whom one could bring problems and that he could communicate with the universe through various means including "telecommunications, biotics and polaris." He was convinced that royalists were doing all this and were cheating him of his rightful inheritance of money and the crown of England.

Results

Of the 480 individuals identified, 23.8% were in-patients and 76.2% were resident in the community. Of the total population, 30.8% attended psychiatric out-patient departments and only 2.9% psychiatric day hospitals; 26.4% were under the care of the community psychiatric nursing service and 1.4% were resident in homeless person hostels.

The point prevalence figure is 8.89 per 1000 on a total population of 54,000. The Nithsdale Survey,[8] in a rural area of Dumfriesshire, employed a similar methodology to our survey and found a point prevalence of 2.38 per 1000 on a total population of 56,000. The higher figure in the present study is indicative of the difficulties facing an inner-city area and has practical implications for the provision of comprehensive services for the longer-term mentally ill.

Case register—'Safety Net'

The logical progression from the survey with a view to maintaining the clinical relevance of the data collected is to establish a suitable case register.[9] We are currently seeking funding for an interactive micro-computer based psychiatric services register to be called 'Safety Net'.

A case register is a cumulative record in which structured data are collected prospectively by mental health workers from specified service delivery points. The proposed register would be aimed primarily at the clinical monitoring of the longer-term mentally ill and at co-ordinating multiple professionals.

New patients are added to the register and a detailed questionnaire completed (similar to the survey data). With each subsequent contact, dated information relevant to that contact is incorporated. All information will be archived, thus providing a longitudinal perspective on each individual.

Of particular interest would be the possibility of having a mental state assessment incorporated at each contact with a psychiatrist thus providing an opportunity to examine an individual's clinical status over time. We recognise that standardisation would be a problem but the Manchester scale[6] could be useful and psychiatrists trained in its use without too much difficulty.

Features of the sytem will include routine and at-risk report generation for users and general practitioners. An up-to-date profile on patient's clinical status and contacts with the service and information for evaluation and research would be an integral part of the system. In order to conform to the requirements of the Data Protection Act and because of the sensitive nature of the data, password protection, data encryption, and a transaction log could be incorporated.

There already exists a patient administration system at

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Friern Hospital based on a multi-user Unix operating machine and it would be desirable to have compatibility with other Friern user districts. The system will provide ongoing evaluation of the developments within the community.

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Videotape Reviews

War Neurosis: Netley and Seale Hall 1917–18 (UK, black and white, 1917, 26 mins)

Although this film is silent it is well sub-titled and is one of the earliest examples of psychiatric clinical recording on film. It was professionally made and very well photographed for the period. After 70 years its condition is probably more presentable than some contemporary videotape recordings will be in 2025.

It shows various tics, spasms, hysterical paralyses and abnormalities of gait in service personnel arising from the stress of war. One patient constantly responded to the word 'bomb' by diving under the bed. Responses to treatment, which largely consisted of suggestion and 're-education', are shown, one case of monoplegia being 'cured' in just 15 minutes! Aspects of occupational therapy, including farm work, are illustrated and the film ends with a battle sequence acted and produced by the patients themselves—one of the earliest examples of psychodrama.

This unique archival material gives a valuable perspective on the evolution of psychiatry in the 20th century. The early concept of 'shell shock' becomes more understandable and there are illuminating glimpses of hospital beds, contemporary clothing and the discipline of the period. This film is one of many of psychiatric interest in the British National Film Archive.

Production: Pathé Frères. *Format:* VHS. *Distribution:* Available through the College. (Jane Boyce)

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Neuropsychiatry 1943 (UK, black and white, 1943, 21 mins)

This film was made in the war-time documentary style and shows the treatment of neuroses in an EMS hospital. Although mainly for service personnel, civilians and children were also accepted.

The admission procedure is first shown, followed by medical examinations and extensive psychological testing, upon which there is considerable emphasis. The commentary is illuminating: "The psychologists co-operate closely with the psychiatrists", and "The social workers are there to assist the doctors". The traditional model persists, to the extent that the Medical Superintendent (casually smoking a cigarette) sees each patient and then allocates an appropriate doctor or therapist.

Physical methods of treatment are shown in detail—continuous narcosis, modified insulin, unmodified ECT, I.V. barbiturate relaxation—and the programme of "remedial training", including OT, art therapy and the weekly hospital dance, is illustrated.

It is difficult to identify the intended audience for this film; the assertive commentary suggests a general one, but the identifiable patients and demonstrations of, for example, ECT, would seem to exclude this, even in war-time. However, it offers an illuminating glimpse of the emphasis and priorities at the time, when psychiatry was on the verge of the post-war explosion in physical methods of treatment.

Production: Spectator Films for the British Council. *Director:* Basil Wright. *Source:* National Film Archive. *Format:* VHS. *Distribution:* Available through the College. (Jane Boyce)

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