Psychiatric Morbidity in Older People with Moderate and Severe Learning Disability

II: The Prevalence Study

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We present a prevalence study of psychiatric morbidity in people over 50 years of age with learning disability (LD), using a new semistructured clinical interview specifically for use with people who have LD (the 'PAS–ADD'). Assessment involved parallel interviewing of subject and informant, these two sets of information being combined to reach a final diagnosis using ICD–9 and DSM–III–R criteria. Detection of dementia involved interviews with informants, plus investigation of loss of cognitive function over a three-year period. The experimental sample was a mixed community and institutional group (*n* = 105), including, as far as possible, all people in a single administrative district (Oldham) matching the age and ability criteria. Prevalence of psychiatric disorder excluding dementia was 11.4% (*n* = 12), most of which were depression and anxiety. Seventy-five per cent of these cases were unknown to mental health services. However, immediate care staff were usually aware of the symptoms, although often unaware of their clinical significance. Prevalence of dementia was also 11.4% (*n* = 12), with a combined case prevalence of 21.0% (*n* = 22). The PAS–ADD proved a flexible interview, effective in use with people of varying linguistic level and intellectual ability: 61.9% (*n* = 65) of the sample were able to be interviewed, fully adequate clinical interviews being obtained with a group of 38 people whose mean IQ was only 39. In the remaining 38.1% (*n* = 40), diagnosis relied exclusively on informant data. Overall, the combination of subject and informant data was essential for sensitive case detection.

The previous paper (this issue) discusses the problems of psychiatric interviewing and diagnosis in people with learning disabilities (LD) (mental retardation), and describes the development of a new psychiatric semistructured clinical interview specifically for use with LD individuals (the Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD; Moss & Goldberg, 1991)).

Here we present the findings of a prevalence study of psychiatric morbidity in older people with LD. The study used the PAS-ADD as the primary assessment of mental health, and a variety of other assessments of IQ, functional ability, and dementia. This study was part of a larger demographic study of people with LD over 50 years of age, commissioned by the Department of Health and conducted in Oldham Metropolitan Borough (Moss & Hogg, 1989; Moss *et al*, 1992*a,b*, 1993).

With the general increase in the proportion of elderly people throughout the developed world, the last 15 years has seen a major growth of interest in the ageing of people with LD (Baker *et al*, 1977). Unlike the USA, this academic interest in the UK was not initially paralleled by a corresponding increase in specific provision for older clients. A number of reasons are probably responsible for this slow response. Notably, the funding and legislative framework of UK services is sufficiently flexible that there have been no immediate requirements for service planners to provide specific services for older clients. For example, adult training centres often offer a flexible retirement option, with the possibility that the client remains as long as he or she wishes. Sometimes, a quiet room is specially provided for individuals who wish to be less active in their later years, yet still want the companionship of their day-centre friends.

In recent years, an increasing number of local authorities have been recognising the importance of making strategic plans to cater for the changing age structure of their LD populations (e.g. Greenwich Directorate of Social Services, 1991; South Edinburgh Group, 1992). In order to make these plans effective, policy makers need access to accurate information on population characteristics which have support and resource implications. Questions which need to be answered include: how many people with LD will survive into later life; how their functional level will compare with younger peers; how many will suffer from dementia. These questions need to be answered against a backdrop of a continuing policy of institutional closure. Many people are being invited

to move out into the community at a time of life when many may be beginning to lose the very skills which are essential to the maintenance of an independent life. It is thus essential that we are in the best possible position to evaluate the overall support needs of the older LD population, and the specific needs of individuals.

Although there has for many years been an awareness that people with LD suffer from mental illness, it is only in recent years that the topic has received close attention. Problems of detecting and diagnosing psychiatric conditions in this population, lack of specialist psychiatric training, and lack of understanding of the significance of symptomatic behaviour on the part of carers have all contributed to an overall inadequacy of psychiatric service. If the person with LD is also elderly, the problem becomes compounded. The ageing process can make people increasingly vulnerable through erosion of their coping abilities, and hence make them more susceptible to environmental stresses which can lead to mental illness. Thus, psychiatric disorder can be a major contributory factor in the decision to admit an elderly person to hospital; Gianturko & Busse (1978) showed, for instance, that 50% of US hospital and nursing-home beds were occupied by psychiatrically ill elderly people. At the same time, the most prevalent psychiatric conditions of old age, dementia, and depression, are themselves relatively difficult to detect at an early stage even in the general population (Goldberg & Huxley, 1980). Taken together, the joint contributions of mental illness, ageing, and learning disability point to a group of individuals whose need for support is likely to be considerable, and whose quality of life will remain seriously impaired if their psychiatric problems are not effectively diagnosed and treated.

This paper is concerned with evaluating the prevalence of mental illness in people with LD over 50 years of age, and determining the extent to which care workers and medical services are aware of these problems. Central to this evaluation has been the development of a new semistructured psychiatric interview, designed specifically for use with LD individuals. The previous paper describes the development of the PAS-ADD, and presents findings on the reliability of the patient version of the interview.

Background studies of prevalence

Campbell & Malone (1991) report that prevalence rates for mental illness in people with LD vary from 14.3% to 67.3% according to the definition of the population under consideration and the criteria for determining presence of a psychiatric disorder. In this respect, the inclusion or exclusion of problem behaviour has a major influence. Severe problem behaviour is the most common reason for which people with LD are referred to a psychiatrist, accounting for over half the presentations in the long-stay residents, and a third of the admissions from the community (Day, 1985). However, these problems are often long-term behaviour patterns, rather than illnesses showing a predictable time course. As such, they often do not fit the established criteria for diagnosable psychiatric conditions (Corbett, 1979).

If behaviour disorders are included, the prevalence of psychiatric disorder among people with LD tends to be high, with a large proportion of the diagnoses being personality disorders. Thus, Reiss (1990) found an overall prevalence of 39%, Menolascino (1989) 30%, and Iverson & Fox (1989), 35.9%. However, if people whose only form of disorder is a behaviour disorder are excluded, then the prevalence of psychosis and neurosis combined appears to be as low as 8–10% (Heaton-Ward, 1977). This discrepancy would tend to be lower in older groups, since older groups show a lower rate of behaviour problems than younger ones (Day, 1985; Kiernan & Moss, 1990).

The study of Lund (1985) is one of the best epidemiological studies of this population which is currently available. He studied 302 adults representative of the total Danish LD population, of whom 94 were aged 45 years and over. In this older group, dementia (14%) was the most common disorder, followed by behaviour disorder (5%), affective disorder (3%), and schizophrenia (3%).

It has been noted that there is a general reduction in prevalence of all types of psychiatric disorder with age (Corbett, 1979; Day, 1985). Day also reports that the overall proportion of admissions aged 40 years and over was less than half that of non-handicapped people in the same age range. This may partly reflect the differences between psychiatric service take-up in handicapped and non-handicapped individuals, the complex of factors which leads people to seek psychiatric help (Hogg et al, 1988) and the pivotal role of the general practitioner (GP) in filtering people through to psychiatric services (Goldberg & Huxley, 1980, 1992).

Overall, it is difficult to make comparisons between studies because of the differences in age groups and populations under consideration. The studies by Lund (1985) and Corbett (1979), for instance, used different diagnostic criteria for mental illness; Lund used modified DSM–III criteria (American Psychiatric Association, 1980) and Feighner's criteria (Feighner et al, 1972), and Corbett used ICD–8 criteria (World Health Organization, 1967). The study

by Day (1985) is not a community prevalence study, since it used a study population combining long-stay hospital residents with community admissions to a psychiatric unit within the same hospital. It is not surprising, therefore, that Day found high prevalence rates for a variety of disorders.

Method

The broad aim of the study was to observe prevalence in a community sample whose membership was defined primarily on a criterion of developmental level, rather than on the grounds of agency contact. This necessitated an extensive exercise to locate individuals who were neither in contact with the Community Support Team (CST), nor resident in a mental handicap hospital.

A variety of assessments of sample members were made, the main measure of mental health being by PAS-ADD interviewing of subject and key informant, described in the previous paper (this issue). Characterisation of the ability stratification of the sample was achieved through measures of IQ and adaptive behaviour. Assessment of dementia was made through a combination of informant interviewing and assessments of cognitive loss, this latter assessment being conducted over three years. Results of the dementia assessments are presented briefly in this paper, and discussed in full elsewhere (Moss et al, 1991).

The PAS-ADD

The PAS-ADD, its development, and reliability are discussed fully in the previous paper. Briefly, it is a modification of the Psychiatric Assessment Schedule (PAS; Dean et al, 1983; Gask, 1988), this latter instrument being based on the 40 items of the Present State Examination items (PSE; Wing et al, 1974) designed to elicit basically neurotic symptoms, with the addition of extra items in order to make it capable of making DSM–III–R diagnoses relating to major depression, generalised anxiety, dysthymia, panic disorder, and agoraphobia (American Psychiatric Association, 1987).

Apart from simplification of wording, the PAS-ADD has a number of novel features:

(a) parallel patient and informant interviewing, these two sets of data being combined to increase sensitivity

(b) a three-tier structure, designed to make the interview flexible for use with a wide range of linguistic abilities; the middle tier is a group of simpler 'core' items identified as the minimum item set necessary to make diagnoses of the principal diagnostic categories; these items become the focus of the interview if the subject's intellectual and linguistic level is sufficient to conduct a clinical interview of partial adequacy

(c) the use of a memorable 'anchor' event in the subject's life, which helps focus discussion on the four weeks immediately before the interview

(d) reorganisation of the items to maximise ease of interviewing with LD individuals

(e) clear visual cues for the interviewer to the conditional jumps which are to be made if a previous question or series of questions has indicated that a line of questioning can be terminated; this increases the focus and efficiency of interviewing, minimising the risk of loss of attention by the patient.

Assessment measures of IQ, functional skills, and dementia

IQ and adaptive behaviour

Adaptive behaviour information was collected on all sample members using the AAMR Adaptive Behavior Scale (ABS; Nihira et al, 1974). Part I of this scale provides information on 24 domains of self-care and community skills. Part II provides information on 13 domains of maladaptive behaviour. The instrument, containing 66 questions in Part I and 43 in Part II (excluding 'use of medications') is for completion by informants.

Assessment of intellectual ability was through use of a version of the Kaufman Assessment Battery for Children (K-ABC), modified to be age appropriate for adults (Hogg & Moss, 1993). Direct assessments of IQ were available on 50% of the sample. However, we were able to show a high correlation (0.72) between these data and ABS scores using multiple regression analysis (Moss et al, 1992). Using the multiple regression solution we were able to project estimated IQ scores for those people who had not been assessed using the K-ABC.

Assessment of dementia

Detection of dementia cases proceeded in the following way. Firstly, the entire sample were screened for potential dementia by interview with a key informant. Secondly, key informants of persons who were suspected, on the basis of this initial screening, to be suffering from dementia were given a standardised interview for informants (Jorm & Korten, 1988). This interview deals with changes in memory and intelligence over the previous ten years. Since, in the present sample, informants with a ten-year knowledge of the subject were rare, flexibility in relation to the time period had to be adopted. Thirdly, potential cases of dementia derived from this interview were given a re-assessment of functional ability using the ABS. The original ABS assessments had been performed on all sample members approximately three years previously. In this present study, any individuals suspected of suffering from dementia, on the clinical grounds described above, were re-assessed on the same instrument. From the multiple regression technique mentioned above, a measure of cognitive change was derived from the ABS data. Significant cognitive loss was taken as confirmatory evidence for the clinical diagnoses.

The study sample

The study sample was originally constituted three years previous to the present study in the context of a project on the demographic characteristics of older people with LD, commissioned by the Department of Health. As a result, we

already had extensive information on IQ and adaptive skills. This retrospective information was used, as mentioned above, in connection with the assessment of dementia, looking for significant loss of intellectual ability over the three-year period.

The sample consisted of people over 50 years of age who lived in, or originated from, Oldham Metropolitan Borough, a town of approximately 225 000 people in the north-west of England. The total identified sample consisted of two groups: those currently in contact with specialist services for people with LD (the CST); and those who were currently not, or who had never been, in contact. This second group was identified through a comprehensive outreach exercise (Horne, 1989) in which contact was made with a wide variety of statutory, voluntary, and private agencies. Staff were asked to identify individuals who appeared to match a broad definition of LD which we furnished. The definition was designed to be over-inclusive, appropriate sample members being selected through subsequent evaluation of their functional level. The extent and coverage of the agency contacts which were made ensured that virtually all people matching the criteria were known to us by the end of the outreach exercise. The aim with respect to selection of outreach individuals was to include people whose level of functioning was in the same range as those in contact with the CST. Thus, people identified by the outreach procedure whose estimated IQ was higher than the top of the range for people in contact with the CST were excluded from the study.

A total of 110 people matching the sample criteria were identified, 105 of whom agreed to participate in this study. Seventy-nine of the 105 sample members were located via their current contact with Oldham CST; the remaining 26 were located via the outreach procedure.

Procedure

For each sample member, a key informant was identified as the individual best placed to answer questions on the subject's mental state. Mental health assessments were conducted at the subject's residence or at the day centre, by a psychiatrist of Senior Registrar status. The clinician had extensive experience of working with LD patients, and was closely involved in the development and piloting of the PAS-ADD.

IQ tests (conducted during the earlier project) were conducted by a clinical psychologist. ABS forms were completed by the key informant.

Results

There was a larger overall preponderance of men (58.1%) compared with women (41.9%). The higher preponderance of men in contact with a mental retardation agency has been noted elsewhere (Moss, 1991). A sizeable proportion of individuals (29/105) were resident in long-term mental handicap hospitals, many of whom had been there most of their lives. In addition, nine people had moved from long-stay hospital to the community within the previous seven years, a majority into independent residences established as part of Oldham's resettlement plan.

Table 1
Age-by-sex distribution of the sample

| | Age band : years | | | |
	50–59	60–69	70–79	80+
Male	21	27	10	3
Female	13	20	6	5

Table 1 shows the sex and age-band distribution of the sample. There was no significant difference in the age distribution of the sexes.

IQ banding for the sample, on the basis of ABS classification, was as follows: 54.4% in the moderate range; 35.0% in the severe range; and 10.7% in the profound range.

Success of clinical interviewing

The sample was quite heterogeneous regarding verbal language ability, ranging from the excellent verbal comprehension and expression demonstrated by a few individuals, to a small number who were totally non-verbal. The introductory portion of the interview was an open section in which background information such as name, date of birth, age, address, and so on, was discussed, followed by questions to assess the individual's grasp of time concept. The subjects were asked about what they had done the day before, where they had gone, with whom they had gone, whom they had seen, and so on. They were thus gradually encouraged to talk about the sort of things they had done over the past month, especially activities or holidays which they had recently been on or enjoyed. There was also an open question about any problems or difficulties over the past month. In response to initial probe, many subjects answered "no", but later revealed significant problems when asked further questions relating to specific aspects of worry, anxiety, and so on.

Even in the cases where subjects had reasonable language ability, there were some who answered only minimally and needed a lot of prompting to elicit sufficient information for rating an item. Others gave information beyond the formal demands of the question. Some appeared pleased to be able to talk to someone on a one-to-one basis, and appeared not to have had such opportunities in the past. Some individuals, despite reasonable language ability, found it difficult to express their views and opinions in an interview situation, or talk about their feelings. Some subjects seemed suspicious about the interview procedure, and needed repeated reassurance and explanation about the purpose of the interview and confidentiality of the information.

Table 2
Numbers of subjects completing the three tiers of the PAS-ADD

Sections completed	n
Tier 1 only (unable to be clinically interviewed at all)	40
Tiers 1 and 2 (core items)	14
Full interview	51

Table 3
Relationship of account of symptoms with subject IQ

Rating of subject's account of symptoms	Mean IQ	n
0 Subject responds adequately	39.2	38
1 Account somewhat inadequate but interview can proceed	32.4	14
2 Account seriously inadequate but interview proceeds in an attempt to rate some subjective responses	28.4	13
3 Impossible to continue with interview	25.1	40

In terms of the three-tier structure of the PAS-ADD, the number of subjects completing the various sections was as shown in Table 2.

The interviewer's estimate of the adequacy of account of symptoms (item 2 of the PAS-ADD) was found to relate consistently with subject IQ (Table 3).

Estimates of prevalence

Among the various indices which could be used for defining cases are:

(a) computer-generated diagnosis from DSM-III-R and CATEGO (ICD-9; World Health Organization, 1978) algorithms

(b) the interviewer's clinical judgement

(c) recognition by usual medical services.

The third of these will be considered within the context of the overall presentation of results, where it will be shown that the majority of cases we identified were hitherto unknown to psychiatric services. The main statistical treatment relates to the computer generated algorithms. However, it must be remembered that the interviewer was a highly experienced psychiatrist, whose clinical judgement is therefore also an important and valid measure of prevalence. These clinical diagnoses will therefore also be discussed and compared with the computer diagnoses.

Table 4
The 12 cases identified by computer algorithms performed on subject and informant interviews

Subject number	Identified by	
	Subject interview	Informant interview
006	D & C	
030		D & C
*047	D & C	D & C
048		D & C
050		C
058	D & C	
059		D
*062	SCAN	D & C
*065	D & C	C
082		D & C
089	D & C	
093	C	

*Good agreement between subject and informant interviews.
D = DSM-III-R algorithm; C = CATEGO algorithm; SCAN (World Health Organization, 1992).

Table 5
Distribution of cases by subject interview adequacy and identifying interview

Level of interview completion		Which interview identified the case		
	n	Subject only	Informant only	Both
Complete interview	51	4	2	1
Partial interview (focus on core items)	14	0	1	2
Unable to be interviewed	40	–	2	–

The diagnostic algorithms

Computer diagnoses were generated from the PAS-ADD data using CATEGO (ICD-9) and DSM-III-R algorithms. Both of these provide computer diagnoses of definite cases. The DSM-III-R algorithm generated, in addition, a total PAS-ADD symptom score which we subsequently used as one of the measures of psychiatric morbidity. CATEGO, in addition to diagnostic categories, generates an index of definition for each subject, and a listing of the scores obtained for each of the 13 CATEGO syndromes available from the 40 PSE items. The index of definition was also used in subsequent analyses as a measure of morbidity.

For the CATEGO algorithm, an index of definition of four was taken to indicate a borderline condition, an index of five representing a definite diagnosable case. Generally speaking, there was a high degree of agreement between the two classification systems (Table 4), most of the disorders being located by both CATEGO and DSM-III-R. Note that one individual, subject 062, triggered the psychotic screening item in the PAS-ADD and was subsequently diagnosed as manic depressive by the Schedule for Clinical Assessment in Neuropsychiatry (SCAN; World Health Organization, 1992).

Table 5 shows which of the interviews (subject, informant, or both) identified each of the 12 cases.

Diagnoses

In terms of the three indices of caseness – that is the computer algorithm, clinical judgement, and prior recognition by usual medical services – the basic findings are presented in Table 6.

Prevalence based on computer diagnoses

At the present time we do not have an established framework for determining the relative validity of information derived from the subject and informant interviews. Indeed, it is difficult to see how such comparative judgements could be made, unless there were compelling evidence from a source external to the interviews themselves. We thus consider the best estimate of prevalence to be the percentage of cases derived from *either* interview or algorithm. This corresponds to 12 individuals (the first 12 entries in Table 6), giving rise to a prevalence estimate of 11.4%.

Table 6
Research and clinical diagnoses[1]

Subject number	Clinical diagnosis using all available information	Research diagnosis using PAS-ADD only	Known to medical services (GP/psychiatrist)
006	Agoraphobia	Panic disorder with agoraphobia	No
059	Agoraphobia, abnormal illness behaviour	Agoraphobia without panic attacks	No
058	Generalised anxiety disorder (GAD)	GAD	No
089	GAD	GAD	No
050	GAD	GAD threshold (CATEGO index of definition = 4)	No
047	Depressive illness secondary to long-standing agoraphobia	Major depression, panic disorder with agoraphobia	No
048	Depressive illness	Major depression	No
065	Depressive illness	Major depression	Known to GP only On low dose of antidepressant medication
082	Dysthymia, paranoid personality disorder	Dysthymia	No
093	Bipolar affective illness, currently depressive	Major depression	On lithium and antidepressant medication
062	Bipolar affective disorder, currently manic	Hypomania	On lithium and antipsychotic medication
030	Dementia, ? depressive illness	Major depression, dementia	GP only, on no antidepressant
024	Chronic schizophrenia, ? dementia	Dementia*	On no psychotropic medication
054	Paranoid schizophrenia	Nil	On depot neuroleptic medication
045	Frontal lobe syndrome, severe problem behaviour	Dementia*	On low-dose antipsychotic medication
033	Severe problem behaviour of unknown aetiology	Nil	On low-dose antipsychotic medication

*Diagnosed by evidence of cognitive loss over a three-year period.
1. Note that the bottom four rows are additional cases not located by the PAS-ADD.

Level of agreement between subject and informant interviews

While the above seems an appropriate basis for a prevalence estimate, it should be noted that close agreement between subject and informant interviews occurred in only three of 12 cases (Tables 4 and 5). This lack of concordance deserves some discussion.

Cases identified by informant interview only

For the five individuals identified by informant interview only (Table 5), three of the cases are explained by the fact that the subject could not be interviewed, or gave an inadequate clinical interview. For example, subject 030 on interview looked sad, with a markedly retarded posture. He spoke little, mainly in whispers, and was disorientated in time and place, with poor memory and little awareness of his surroundings. With subject 082 it was difficult to build any rapport despite his reasonable language ability. He appeared unconcerned about the interview, actively avoiding eye contact. He would often say "yes" before a question was completed and repeatedly asked when he could go to the day centre nearby, although he never attended. Subject 050 was tense and apprehensive during the interview and seemed to find it particularly difficult to confide her worries to a relative stranger. In this case the informant was able to describe clearly the subject's anxieties, especially when meeting new people or waiting in a queue. When anxious, the subject was sweaty, shaky, jumpy, and would continually pace up and down wringing her hands. She would also noticeably start breathing rapidly and her concentration on tasks would deteriorate. She also seemed particularly anxious when meeting 'authority' figures, such as social workers, doctors, or dentists. Subject 059 denied feeling unduly sad or anxious or exhibiting any avoidance behaviour. The informant, however, had noticed that the subject was overtly anxious when in crowded places, for example while shopping or on the bus, and had developed a routine whereby he avoided going to town on Saturday mornings and would only travel on the bus during off-peak hours.

Cases identified by subject interview only

Two of these cases had a total PAS-ADD score of 0 on the informant interview yet were identified as cases on the subject interview. Subject 006 clearly described both psychic and somatic symptoms of anxiety with panic attacks and actually had a panic attack during the interview. The informant, however, thought that the subject was histrionic and had a tendency to exaggerate her worries. She had in the past deliberately made up stories to avoid getting into trouble. The informant did concede that the subject was extremely anxious when she first came to the hostel, but had improved since then. Subject 058 was able to give a clear account of his irrational excessive worry that something terrible might happen to his sister, while the primary care-giver gave details about autonomic symptoms

accompanying these worrying thoughts. The informant in this case had known the subject for many years, but did not, however, think that anything serious was wrong as the subject appeared well adjusted and never complained of anything. Subject 089 gave a clear account of her worries, which appeared out of proportion to the circumstances. These worries were accompanied by both psychic and somatic symptoms of anxiety, which tended to be worse at night when she was on her own, and prevented her from getting off to sleep. The informant, although aware that the subject had suffered from similar symptoms in the past, did not realise that they still troubled her, these problems manifesting themselves mainly during the night.

Prevalence based on clinical diagnosis

The interviewing psychiatrist's clinical opinion was in agreement with the 12 cases identified by the PAS-ADD. In addition, Table 6 also indicates four further cases, identified on clinical grounds, which were not identified by the computer algorithms. Evidence for the two cases of schizophrenia came from previous psychiatric records and predominant negative symptoms on mental state examination: thought disorder, social withdrawal, poverty of speech, self-neglect, and loss of volition. Neither of these subjects had acute psychotic phenomena, that is delusions and hallucinations. One was currently receiving antipsychotic medication under psychiatric supervision. The other had been resettled from a long-stay mental illness hospital to an elderly person's residential home, and had a clearly documented history of auditory hallucinations. Interviewing her was extremely difficult due to a combination of poor hearing and marked loosening of associations in her thought processes. This subject also received a research diagnosis of dementia.

The other two subjects were clinically thought to have severe problem behaviours needing specialist intervention. One of these presented a clinical picture of 'frontal lobe syndrome' and had a research diagnosis of dementia. The other subject has subsequently died. The exact aetiology of the behaviour disturbance here remained unknown.

It can thus be seen that a prevalence estimate based on clinical impression would be higher than that based purely on PAS-ADD data alone, the 16 cases in Table 6 representing a prevalence of 15.2%.

Sensitivity of case detection

Within the present study we do not have available an independent estimate of prevalence which could be used as a yardstick for comparison with case detection based solely on PAS-ADD data, for example independent judgement of a second clinician. However, the project interviewer (who was himself an expert clinician), was of the opinion that two further cases may have been undetected by the interview; that is the two cases of possible schizophrenia described above (see Table 6). While it is doubtful whether these individuals' symptoms were currently active, this is nevertheless an indication of the unavoidably lower sensitivity of case detection based solely on interviews, compared with the in-depth process of clinical judgement.

This important evaluation of sensitivity is being further explored in the current phase of development, described in the concluding section.

With regard to the interview data itself, some further consideration needs to be given to the amalgamation of subject and informant data, particularly in those cases where the clinician had judged the subject's interview to be inadequate. Two questions which arise are (a) was it possible to identify cases on the basis of an inadequate partially completed interview, that is the core items only; and (b) could a more effective amalgamation of patient and informant data raise the sensitivity, and hence identify further cases which had hitherto not been recognised?

In exploring these questions we included only the 12 cases located by computer algorithms; our confidence in these diagnoses was high since they were also confirmed by the clinical judgement of the interviewer.

(a) Inadequate/incomplete patient interviews

In relation to the adequacy of subject interviews, it is (generally) easier to obtain a good interview if the subject is intellectually more able. This has already been shown by the relationship between IQ and the adequacy of interview as rated by the clinician (Table 3). Not surprisingly, this relationship was further reflected in a significant difference in the IQ of cases versus non-cases. Mean IQ of the 12 cases was 39.2, that of the non-cases 29.3 (t-test, $P<0.005$).

The same effect occurred in those cases identified solely on the basis of informant interview, although not statistically significant (IQ of non-cases = 25.0, IQ of cases = 28.0). It seems likely that the lower rate of detection among the less able members of the sample related not just to the possibility of successful interviewing but also to the difficulty of identifying psychiatric symptoms in people whose level of handicap is severe. This applied not just to the examining psychiatrist but also to informants who knew the individual well.

When the clinical interview could only be partly completed, there was naturally a reduced amount of information from which the computer algorithms could derive a diagnosis. Nevertheless, it *was* possible to identify two cases by *subject* interview on the basis of a partial interview focusing mainly on the core items (Table 5).

(b) Amalgamation of subject and informant data

Up to this point, computerised case detection has been based on two separate sets of data, the subject and informant data being regarded as independent. Individuals have been designated as cases if either interview produced a positive result. The question arises, however, of whether it is helpful to supplement missing subject data with informant data to provide a more complete picture of the symptoms. This was therefore tried, but it was found that replacement of missing values in the inadequate subject interviews with the corresponding value from the informant interview made no substantial difference to the PAS-ADD total symptom scores, presumably because the clinician had tended to rate symptoms as not present (i.e. 0) rather than unrateable (9).

We therefore took a more radical approach, deriving the 'worst case' data set from the two interviews. This involved

replacement of subject ratings with informant ratings whenever the latter was more indicative of symptoms being present. Following these substitutions the algorithms were re-run and changes in the PAS-ADD, total score and index of definition noted. Even under these circumstances, no new potential cases came to light. Previous disagreements, where subject interview had indicated few symptoms while the informant data indicated a firm case, naturally reverted to the informant position. Apart from this, no subjects showed clinically significant changes in symptom scores.

At first sight it seems surprising that this worst-case approach produced no new cases. However, this may be because the clinician does not ask the interview questions as if they are each totally independent. Rather, an investigative approach is used, in which experience and intuition play a part in forming hypotheses which are explored during the interview. Items essential to making a decision would tend to receive much attention, the overall effect being to reduce the proportion of interviews giving a borderline result.

Awareness of psychiatric conditions by informants, and current treatment being received by identified cases

Only three of the 12 identified cases (25%) were already receiving psychiatric treatment for their disorder. All three of these had a more severe mental disorder, one being diagnosed as having manic–depressive illness and seeing a psychiatrist. Another had a major depression with cognitive decline and was being treated by the GP, but on a low dose of antidepressant medication. The third was in a hospital for the mentally handicapped, receiving treatment for major depression.

There were thus nine subjects (75%) who were not receiving any treatment. In six of these cases, the informants *were*, however, aware of the symptoms. These subjects were not receiving any medical help partly because the informants did not understand the significance of the symptoms, or thought they were not severe enough to merit seeing the GP. In one case, where the individual had a severe agoraphobia and was totally housebound, the informant was helpless because the subject refused to see her GP. She had received treatment in the past for similar complaints, but with little success due to poor compliance. Another subject had major depression and would have benefited from further medical intervention. The informant here, although aware of the subject's distress, was unable to decide whether referral to the GP was necessary. Of the remaining four who would have benefited from further medical intervention, the diagnoses were: agoraphobia, generalised anxiety disorder (GAD), dysthymia, and major depression.

In three of the identified cases, even the informants were unaware of the current symptoms. These were all cases of anxiety (one of agoraphobia, and two of GAD) (cases 006, 089, 058). In two of these cases, however, the informants were aware of previous episodes of anxiety.

Dementia

Based on the evidence of Jorm & Korten's (1988) dementia checklist, plus additional evidence from informants,

16 individuals were judged to be probable cases of dementia. ABS assessments were repeated on these 16 suspected cases to generate a measure of cognitive ability which could be used to look for significant changes over the three years since the original assessments were made.

Full details of these statistics, and the results, are presented elsewhere (Moss *et al*, 1991). Briefly, 12 of the 16 cases were confirmed as showing a significant functional decline, representing a prevalence rate of 11.4%. Four of these 12 confirmed cases had Down's syndrome. This, out of a total of nine individuals with Down's syndrome in the entire sample, shows the high risk for these individuals (44%). At the same time it is notable that five of the nine did *not*, from a clinical and behavioural point of view, suffer from dementia; available evidence suggests that they would nevertheless manifest the histopathological signs of the disease. This is an indication of the imperfect association between brain pathology and dementing behaviour noted by others (Solitaire & Lamarche, 1966; Olson & Shaw, 1969; Burger & Vogel, 1973; Ellis *et al*, 1974; Zigman *et al*, 1990).

Combined prevalence estimate

While the psychiatric and dementia cases each included 12 individuals, two people overlapped these categories. A total of 22 individuals thus received a computer diagnosed psychiatric condition, or a diagnosis of dementia confirmed by significant loss of cognitive function over the three-year follow-up. This represents a combined case prevalence of 21.0%.

Discussion

The PAS-ADD

Considering that our sample did not include individuals with mild LD, it was reassuring to note that so many were able adequately to complete the subject interview, considerably more than were expected by the interviewer from his clinical experience to date. The flexible three-tier structure was found to be particularly useful in this respect. A more rigid structure would have inhibited the development of rapport with the subject, and probably led to higher acquiescence and suggestibility. While we would not suppose that such problems have been (or even can be) eliminated, the organisation of the PAS-ADD was a definite aid in this respect.

A crucial issue relates to the major disagreement between diagnoses based on subject and informant interviews. Some of these disagreements can be accounted for by the fact that some of the clients could not be interviewed, while the informants clearly could. Those cases where the subject demonstrated symptoms, while the informant saw no problems, probably indicate a lack of awareness of the psychiatric problem on the part of the informant.

It is not surprising that this type of disagreement occurred in a number of cases, given the difficulty of separating psychiatric symptoms from behaviour relating to mental handicap. Our work on developing interview skills with this population, through practice, discussion, and reviewing of videotapes, has shown the importance of experience and training in making reliable and valid diagnoses in this population. Although the quality of informant data was generally good, one could not expect the informants to have the expertise of a mental health assessor trained specifically in this discipline.

While it is clear that information from key carers is important and sometimes crucial in arriving at a diagnosis, there are questions concerning the validity and reliability of such information. The informant may have a close relationship to the patient, yet be unobservant or unable to provide accurate information on the time course; information passed on to the informant by other carers/professionals may lead to bias in reporting; the informant may actively dislike the patient, and hence give a more negative picture of the individual's difficulty than may be the reality. In addition, factors such as informants' knowledge of mental illnesses in general, their past personal and family experiences of mental illness, attitudes to prescribed drug use, and experiences of asking for help from medical services in the past, may bias the information they give.

The phenomenon of 'diagnostic overshadowing' is also an important consideration in relation to both psychiatrists and informants, that is that the presence of LD increases the significance of accompanying mental disorder symptoms (Reiss *et al*, 1982). In the present study there was some evidence of this effect occurring; informants, although aware of distressing symptoms in most cases, tended to underrate their significance.

Prevalence estimates

From the above, it is clear that the estimate of prevalence is sensitive to the way in which information from subject and informant interviews are combined. In addition, however, an important variable is the ability level of the population; it is easier to detect psychiatric morbidity in a more able individual than in a less able one. This applies not just to face-to-face interviewing with the subject, but also to data elicited from informants. Informants, therefore, also find symptom patterns more clearly visible in people of greater ability. As a result, we found that the group of cases had a higher average ability level than the non-cases. We are not in the position to estimate how far this effect extends beyond the moderate/severe handicap level; in this respect it would be of benefit to extend the study to include people whose level of handicap is less severe.

The validity of comparison between prevalence rates quoted in other studies is often difficult to establish because the exact criteria for detection and diagnosis tend not to be described. The study of Lund (1985) is one of the best in this respect; he used DSM–III criteria (although the exact methodological details and criteria were not given). Lund found an overall prevalence of mental disorder in his 45 + subgroup of 29.7%. If behaviour disorders are excluded the prevalence rate declines to 24.5%, which is comparable with our combined estimate of 21.0% for dementia and other disorders. The most prevalent disorder in Lund's study, as in ours, was dementia (14.1% compared with 11.4%). Also in line with Lund's findings, our study revealed no cases of autistic disorder (DSM–III–R), alcohol, or drug dependence.

Lund found a prevalence of 6% for affective disorders, a broad category which does not compare directly with our specific diagnostic categories. However, the total number of cases in the present study where depression was primary or secondary, plus the one case of dysthymia, is five (4.8%); given the margin of error, this is a comparable finding.

Our finding for the prevalence of primary anxiety related disorders is 5.7%, a figure considerably above that of Lund's figure of 1.5% for neuroses. This discrepancy may of course indicate differences in the categories used by Lund and ourselves. On the other hand, it supports the assertion of Sovner & Hurley (1983) that anxiety and panic disorders tend to be underdiagnosed in the LD population.

A major difference between the two studies is the much higher prevalence reported by Lund for problem behaviours (10.9% versus 1.9%). Such a huge difference must reflect differences in the classification of such behaviours, and cannot therefore be interpreted without further information. In the present study, the diagnosis was only applied to *severe* problem behaviours, a classification which applied to only two individuals. It is likely that Lund's criterion was much more encompassing.

Conclusions

Although there remain a number of unresolved issues concerning detection and diagnosis in this population, it is clear that the study sample manifested a range of psychiatric conditions, many of which were unknown to psychiatric services. Two related factors are likely to have been particularly important in producing this relatively high proportion of untreated cases. Firstly,

most of the disorders detected in this older population were neither psychotic, nor within the range of conditions where odd behaviour patterns are liable to draw attention to the individual. Rather, the majority of cases were of depression and anxiety, conditions which are also underdetected in the general elderly population (Goldberg & Huxley, 1980). Secondly, the probability of a person with LD being referred to the GP for psychiatric problems is lower than for a non-handicapped person. For a non-handicapped person, onset of a mental illness is often heralded by being unable to hold down a job effectively, or being unable to fulfil roles which had previously been carried out successfully, for example by a parent, spouse, or friend. In comparison, people with LD tend to have lower role expectations, so the impact of mental illness on everyday life is less clear-cut. Without specialist knowledge it may be assumed that the symptoms are part of the general handicapping condition; thus, referral to the GP for further psychiatric evaluation may not be made.

While the need to make appropriate referrals remains a problem, it was also found that care staff can give high quality information on the mental state of their clients, this information often being crucial in arriving at a diagnosis. However, while it is clear that care staff are usually aware of the symptoms, they do not always realise that the symptoms are indicative of a psychiatric disorder. Nevertheless, this awareness is encouraging, since it suggests that an appropriate training package which capitalises on this awareness could achieve major improvements in community psychiatric services, by improving the likelihood that people in need of psychiatric attention are referred to an appropriate professional.

Although it was not possible in the present project to assess the impact of untreated mental illness on the level of support required, it is well known that mental health is an important factor in the ability of older people to live independently in the community (Gianturko & Busse, 1978). In addition, our data on the physical health of this population, (Moss *et al*, 1992) showed that the group suffering from dementia had much poorer physical health than the group average. Health index measures indicated poorer scores for both chronic and acute physical disorders, particularly those involving the central nervous system and gastro-intestinal functioning. Many of the individuals with a firm diagnosis of dementia showed deterioration in a wide variety of self-care and community skill domains. This, coupled with their generally poor health, suggests that the level of these people's needs represents a major use of social service resources.

Ongoing developments

Continuing development of the PAS-ADD is being funded by the Department of Health, the overall aim being to provide a comprehensive ICD-10 clinical interview and accompanying glossary. In the current phase of development (Moss & Goldberg, 1991), the range of the PAS-ADD will be expanded to include the principal diagnostic categories of people with LD seen by psychiatric services. The expanded PAS-ADD will permit ICD-10 diagnoses of: F20 schizophrenia; F32 depression (severity at least F32.0); F40 phobic anxiety disorders; F41 other anxiety disorders; and F84 pervasive developmental disorders.

Overall, there is still much development and research work to be undertaken, not just in the field of case detection and diagnosis in this population, but also in relation to care staff and their awareness of the significance of diagnostically significant behaviour patterns in their LD clients. In relation to the latter, we hope in the future to develop a package of training materials for use with staff working in community settings. Such materials would take the form of videotapes showing: (a) appropriate interview techniques; (b) techniques to elicit the phenomena of psychiatric disorder in people with mental handicap; (c) interviewing of carers; and (d) examples of the important syndromes of disorder.

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